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An exploration of the experiences and perceptions of young women living with a history of breast cancer in the UK

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Declaration

This declaration states that this thesis and the research on which it is based are the sole work of the author. This thesis has not been submitted for a degree at another university.

Abstract

This thesis explores the experiences and perceptions of young women living with a history of breast cancer in the UK, diagnosed under age 45. Although much research has examined the experience of breast cancer, the distinctive perspectives and lives of young women have been neglected. The literature review identified the following dimensions to living with a history of breast cancer as a young woman as key areas for exploration: embodiment, biographical disruption, gender, and intersectionality. By analysing the significance of intersectionality, the study aimed to redress the tendency in existing research to treat women with breast cancer as a homogeneous group.

Qualitative, semi-structured interviews were undertaken with twenty women aged 22-43 at diagnosis, and a stakeholder panel was held with three further young women. Three women who identified as minority ethnic, and two who identified as lesbians, were purposively recruited to the sample. The methodology was informed by social constructionist grounded theory, feminist, and intersectionality perspectives, and preliminary analysis was carried out concurrently with data collection.

Although similarities with older women's experiences exist, the findings showed that young women felt profoundly at odds with their bodies in a number of ways. These included: embodied risk, related to uncertain treatment outcome; and a dissonance between young women's expectations of their bodies, and the reality. The effects of diagnosis and treatment resulted in a liminal, or suspended, state, because of uncertainty regarding fertility, pregnancy, and menopausal status. This, and the constraints of the treatment timescale, resulted in a perceived loss of agency over their future. Gendered ideals about young women's bodies, the association of fertility with femininity, and the performance of emotion work, had a considerable impact. Reflecting the effects of intersecting social divisions, lesbian and minority ethnic respondents identified a series of disadvantages that they experienced in the course of treatment and care.

The study contributes a deeper, and more nuanced, account to the limited literature about young women in the UK living beyond breast cancer, identifying the distinctive experiences and perceptions which arise for young women.

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List of abbreviations

AU – Australia

CA – Canada

SW – Sweden

SU – Switzerland

TH – Thailand

UK – United Kingdom of Great Britain and Northern Ireland

US – United States of America

BCC – Breast Cancer Care

BCUK – Breast Cancer UK

NBWN – National Black Women’s Network

BME – Black and minority ethnic

LGB – Lesbian, gay, and bisexual

MX – Mastectomy

BCS – Breast conserving surgery

BSE – Breast self-examination

CPM – Contra-lateral prophylactic mastectomy

Chapter One – Introduction

Introduction

This thesis draws on the accounts of twenty young women who participated in qualitative semi-structured interviews, in order to explore the experience of being a young woman with a history of breast cancer from their own perspectives. The study focused on young women's stories with the aim of contributing to the scarce amount of research about the lives of women in the UK diagnosed under the age of 45. In addition to the interviews, young women were engaged in the research through the use of a stakeholder panel, which contributed to the findings of the study. A theoretical framework was developed through an analysis of existing literature, and drew on theories of embodiment, biographical disruption, and gender and intersectionality, in order to explore the distinctive elements of being a young woman with a history of breast cancer in relation to these three key dimensions. Carried out within the interpretive paradigm, the research was underpinned by a methodology informed by social constructionist grounded theory, and methodological and ethical principles of feminism. This facilitated an analysis of the young women's accounts which considered their experiences and perceptions of their bodies, their biography, and the influence of gender and other intersecting forms of oppression.

In this chapter, I first introduce the background to the study and the rationale for conducting it, and, following this, I introduce the theoretical framework for the study. Next, the research questions which were developed from the literature review are presented, followed by an introduction to the methodology and research design. The final section of this chapter contains the thesis outline.

Background and rationale

Breast cancer is the most common cancer diagnosed in the UK, with the lifetime risk for women currently one in eight (Cancer Research UK 2013). Research and writing about women's experiences of breast cancer has increased since the 1980s, alongside the growth in interest in the experience of illness in the sociology of health and illness (Pierret 2003). Yet, the experience of being a young woman with a history of breast cancer, particularly in the UK, remains relatively underexplored. This lack of research may be related to the fact that around 80% of breast cancers in the UK are diagnosed in women over 50 (Lawrence *et al.* 2011). However, the numbers of young women diagnosed each year have been steadily increasing in the UK, and in Europe as a whole (Cancer Research UK 2014a; Merlo *et al.* 2012), and it is the most common cancer diagnosed in women aged 18-39 in the UK. Over 10,000 women under the age of 50 were diagnosed with breast cancer in 2010, compared with around 7,000 in 1995 (Cancer Research UK 2013).

The experience of receiving cancer treatment, and subsequently living long-term with a history of cancer, is becoming more and more common in Western societies. By 2030, the number of people living with a history of cancer in England alone is expected to rise to over 3 million (National Cancer Survivorship Initiative 2013). Breast cancer is the most commonly diagnosed cancer, yet the survival rate is one of the highest, resulting in a large population of women who have been treated for breast cancer. The net five-year survival rate for young women diagnosed with breast cancer in 2007-2011 was 84.8% for women aged 15-39, and 89.4% for ages 40-49 (Cancer Research UK 2014b). Thomas-MacLean (2004:638) argued that “the ramifications of breast cancer and its treatments affect all spheres of life, including appearance, family relationships, moral dilemmas, and interactions with medical professionals”, and the impact continues long after the end of treatment. Living beyond cancer has been referred to as a “dynamic, life-long process” (Pelusi 1997:1353), and research is vital to understand the experience and provide an evidence base for

healthcare services and professionals. The importance of supporting people long-term after cancer is increasingly being recognised as significant for the NHS. A recent report from MacMillan Cancer support (2013) highlighted the long-term consequences of cancer and argued that “we have to recognise that ‘not dying’ [from cancer] is not the same as ‘being well’” (p.2).

A review of the literature revealed that there have been very few published studies in the UK in which the experiences of young women have been specifically explored. In 2001, Lindop and Cannon published a study in which they interviewed twelve women aged 26-58, to inform a subsequent quantitative questionnaire completed by 971 women (57 of whom were 45 or younger). Young women with a history of breast cancer identified more needs in their quantitative study than older women, especially in the categories of ‘femininity’, ‘body image’, ‘family and friends’, ‘information’ and ‘after care’. Unfortunately, Lindop and Cannon provide very little information about their qualitative interviews with the young women. Therefore, although the quantitative element of this study is useful in indicating that age affects the experience of women living in the UK with a history of breast cancer, it did not examine why these categories were important to young women. More recently, young women have been included in UK studies which considered the experiences of women of all ages (e.g. Banning *et al.* 2010; Fish 2010; McCann *et al.* 2010; Tighe *et al.* 2011; Trusson 2013; Patel *et al.* 2014), but young women’s experiences have not been thoroughly separated out in these studies, and the significance of age is often not discussed at all. Lee *et al.*’s (2011) study did explore the perspectives of young women, but only in relation to one aspect of their experience of breast cancer: fertility and their encounters with a fertility health service.

Although there is empirical knowledge about young women’s experiences of breast cancer from other parts of the world, it would be inappropriate to assume that the findings of these studies can be straightforwardly generalised to the UK, given the differences between the

healthcare systems, and the different social and cultural contexts (Patel *et al.* 2014). For example, differences have been found between countries in terms of breast reconstruction, as more women undergo breast reconstruction in Sweden than do in the UK, Australia, or the US (Fallbjork *et al.* 2010), and Fallbjork *et al.* argue that this may be related to the structure of the healthcare systems, but also to social and cultural factors. The social context in which a person is embedded shapes the experience of illness (Pierret 2003; Lupton 2012). There is a strong breast cancer movement in the USA, and there exists a considerable amount of research on the way that this has shaped cultural ideas about breast cancer (see Lerner 2001; Kasper and Ferguson 2002; King 2006; Ehrenreich 2001, 2008; Sulik 2011). Therefore, whilst young women from all over the world may have shared concerns and experiences related to the nature of the disease and its treatments, there may also be differences related to their given national and social context, and it can be argued that the voices of young women in the UK are under-represented in knowledge about the experience of breast cancer. In order to illustrate this, Appendix A provides a table containing the studies cited in the literature review which have used qualitative research methods to explore the experience of breast cancer from women's own perspectives, organised by country in which they were conducted. From Chapter Two onwards, I have used an abbreviation denoting country of origin each time one of these studies is first introduced. A list of these abbreviations can be found on page x.

Theoretical framework

Developed from the review of existing literature, this thesis draws on a theoretical framework of theories of embodiment, biographical disruption, and gender and intersectionality, in order to explore young women's accounts of living with a history of breast cancer. The theoretical context is introduced here in advance of more detailed discussion in subsequent chapters.

Embodiment

Originating in philosophy and phenomenology, theories of embodiment position the body as central to human experience (Merleau-Ponty 1945/2012; Turner 1992). Within the sociology of health and illness, scholars taking an embodiment approach have emphasised the significance of the material realities of pain, suffering, and bodily change to the experience of illness (e.g. Williams 2006; Thomas-MacLean 2005). Embodiment theories are also helpful in understanding that illness is not experienced solely in biological or social terms, but in some combination. Lupton (2012) argued for an approach to understanding illness and the body in terms of both social construction and material reality. She wrote: “experiences such as illness, disease, disability and pain exist as biological realities, but...such experiences are always inevitably given meaning and therefore always understood and experienced through cultural and social processes” (2012:11). Therefore, for example, a woman’s decision to have breast reconstruction after breast cancer is made in the context of what it means in wider society to have lost a breast, but also in the light of the personal bodily experience of having one breast, the physical implications of this, and the emotional loss of a part of the body.

Embodiment has been explored in a number of studies about the experience of breast cancer (e.g. Bredin 1999; Thomas-MacLean 2005; McCann *et al.* 2010; Brunet *et al.* 2013). This research, involving women of all ages, has identified ways that breast cancer treatment shapes embodied experience. For example, it has been found that the meaning of breasts can change for women who have had breast cancer, and they may come to symbolise grief or anxiety (Burles 2010; Piot-Zielger *et al.* 2010). This research can be built upon, in order to deepen understanding of the experiences of young women. In this thesis, I take an approach to embodiment which is informed, in particular, by the work of Young (2005), Lupton (2012), and Thomas-MacLean (2005), in order to explore young women’s embodied experiences after breast cancer, and how they perceive these. This approach considers young

women's experiences and perspectives of their bodies, and takes into account the meanings such experiences are ascribed in their social context.

Biographical disruption

The theory of biographical disruption was developed by Bury (1982), to explain how the onset of chronic illness may be experienced as disruptive to previously taken-for-granted assumptions about everyday life, relationships, and the future. An individual must try to make sense of their experience in the face of this disruption, and so “a fundamental re-thinking of the person's biography and self-concept is involved” (Bury 1982:169). Bury's work has proven influential in sociological work about the experience of chronic and serious illnesses, but there have been critiques of the theory, leading to developments in sociological understanding of illness experience. For example, Bury's work has been challenged by studies that suggest that illness may be experienced as biographically continuous, or reinforcing, by individuals in particular circumstances, such as in the context of a life of hardship and adversity, or in old age (Pound *et al.* 1998; Ciambrone 2001; Sanders *et al.* 2002; Faircloth *et al.* 2004; Sinding and Wiernikowski 2008). The theory has been drawn on in studies about the experience of cancer (Sinding and Wiernikowski 2008; Cayless *et al.* 2009; McCann *et al.* 2010; Hubbard *et al.* 2010; Trusson 2013), but is surprisingly absent from the literature focusing on young women and breast cancer. In research about the experiences of young women with breast cancer, there are mentions of ‘life disruption’ and ‘disruptions to quality of life’ (Shapiro *et al.* 1997; Bloom *et al.* 1998; Dunn and Steginga 2000), but the extent to which young women's experiences and perceptions of living with a history of breast cancer are characterised by biographical disruption, and the nature of this disruption, remains unclear.

The literature review indicated that two further concepts may also be useful in understanding how young women with a history of breast cancer experience and negotiate its impact on

their lives: cancer survivorship and liminality. Women may position themselves as cancer survivors in order to make sense of disruption wrought by cancer (Documet *et al.* 2012; Stephenson *et al.* 2013), but some research indicates that people to whom it would be applied have diverse responses to the term (Kaiser 2008; Khan *et al.* 2012b). It has also been argued that the idea of survivorship places too much emphasis on survival, neglecting the long-term implications for everyday life (Little *et al.* 1998). The concept of liminality was developed in relation to the experience of cancer by Little *et al.* (1998), who posited that people with a history of cancer find themselves feeling neither ‘ill’ nor ‘well’. Rather, they find themselves in an in-between state, living with ongoing effects of treatment, and with the fear of recurrence, but simultaneously assumed by others to be well and returned to normal (Little *et al.* 1998). Researchers studying the experience of living beyond cancer have identified liminality (Little *et al.* 1998; Navon and Morag 2004; Cayless *et al.* 2009; Hubbard and Forbat 2012; and Trusson 2013), but, again, the experiences and perceptions of young women living with a history of breast cancer are missing.

Exploring the distinctive stories of young women living beyond initial breast cancer treatment may, therefore, enrich understanding of biographical disruption, cancer survivorship, and liminality.

Gender and intersectionality

The final strand of the theoretical framework draws on theories of gender and intersectionality. This element of the framework builds on the previous two, taking into account how the impact of breast cancer occurs within a given social context (Kasper 1994; Thomas-MacLean 2005). Feminist theorists have denaturalised ideas about gender and what it means to be a woman, arguing that the gender norms which characterise a society are not natural, but socially constructed, produced and maintained by everyday interactions and social structures (Young 1990, 2005; Kasper 1994; Jackson and Scott 2002; Smith 2007;

Oleson 2011). A feminist approach is adopted in this thesis which understands gender as socially constructed, and explores the consequences of societal ideas about gender for the lives of young women living with a history of breast cancer. This is informed by the writings and research of feminists in the area of breast cancer, such as Lorde (1980), Kasper (1994), and Thomas-MacLean (2005).

Theories of intersectionality were developed as a critique of second-wave feminism, which tended to treat all women as all having a shared experience, without taking into account the ways that other social divisions intersect with gender to produce experiences in everyday life and complex identities (Crenshaw 1989; Phoenix 1990; McCall 2005; Shields 2008). In intersectionality, social divisions are understood not as occasionally intersecting, but as interwoven and connected, mutually constituting one another (Collins 1992). Intersectional analyses have demonstrated how women's experiences and opportunities are different according to where they are positioned within social categories, such as their ethnicity and socio-economic status. Therefore, it is not possible to understand a social category in isolation from others, and gender inseparable from other social divisions (Phoenix 2013). Much existing research has neglected to explore the ways that intersecting oppressions, such as ageism, heterosexism, or racism, inform the experience of living with a history of breast cancer (Fish 2010; Patel *et al.* 2014). There is a growing body of research which has explored black and minority ethnic (BME) women's experiences of breast cancer (e.g. Wilmoth and Sanders 2001; Ashing-Giwa *et al.* 2004; Banning *et al.* 2010; Blows *et al.* 2009; Patel *et al.* 2014), and lesbian women's experiences (e.g. Boehmer *et al.* 2007; Fish 2010; Jabson *et al.* 2011; Rubin and Tanenbaum 2011). However, most of this research has been conducted outside of the UK, and, further, it has not focused on *young* BME or sexual minority women's experiences. This study as a whole aims to redress the relative neglect of young women's experience by exploring the intersection of age and gender. In addition to this, it also aims to contribute to addressing the distinctive experiences of young BME and lesbian women.

Research questions

The above sections have introduced the theoretical framework for this thesis, developed from the literature review, informed by three major elements: embodiment; biographical disruption; and gender and intersectionality. The main aim is to explore the experiences and perceptions of young women living with a history of breast cancer, and three subsidiary questions were also developed through the critical analysis of existing research:

Main question:

- What are the experiences and perceptions of young women living with a history of breast cancer in the UK?

Underlying questions:

- What are the embodied experiences of young women living with a history of breast cancer, and how do they perceive these?
- To what extent does biographical disruption characterise the experiences and perceptions of the young women?
- How are the experiences and perceptions of the young women informed by gender? And are these informed by other intersecting oppressions, such as racism and heterosexism?

As this chapter has thus far demonstrated, taking an approach which draws on three theoretical areas facilitates an analysis of the young women's accounts, which considers their own perspectives on their bodies, their biography, and the influence of gender and other intersecting forms of oppression.

Methodology

A research methodology informed by interpretivism, social constructionism, and feminism was adopted. This methodological framework was identified as in line with the aims of the research questions, and enabled an in-depth exploration and analysis of the young women's

accounts, with the aim of achieving an understanding grounded in their own perspectives, and situated within the wider social context.

Interpretivism

This research is situated within the interpretive paradigm, a perspective which assumes that, in order to understand a social phenomenon, researchers must explore it from the perspectives of individuals experiencing it (Williams 1998; Barbour 2014; Charmaz 2014). Interpretivists, therefore, aim to understand individuals' own actions, understandings, and meanings. They also seek to examine the social context in which individual experience occurs, and how a person's location within wider social structure shapes their experiences and perceptions (Bryman 2008; Charmaz 2014).

Social constructionism

Social constructionists approach research from a theoretical position which assumes that there is no single, discoverable reality, and that individuals ascribe meanings to experiences, and these meanings are shaped by social, structural, and experiential context (Denzin and Lincoln 2003; Charmaz 2006; Green and Thorogood 2014). Rather than using positivist methods to access the 'truth' about women's experiences of, for example, their bodies after treatment for breast cancer, the particular ways that young women understand and view their bodies after breast cancer are best explored through qualitative methods. Consistent with interpretivism, this approach privileges individual understandings and meanings, and also acknowledges that there are wider social and structural forces involved in shaping these (Creswell 2007; Green and Thorogood 2014).

Social constructionist grounded theory

The study's methodology is also informed by the work of Charmaz (2006, 2014), who developed a social constructionist grounded theory method. Grounded theory methods aim

to produce an understanding of a social phenomenon which is led by the data, grounded in the accounts of those experiencing it, and, therefore, resonates with their experience and makes sense to them (Glaser and Strauss 1967; Dyson and Brown 2006; Strauss and Corbin 2008). The original formulation of grounded theory, the “discovery of theory from data” (Glaser and Strauss 1967:2), has been criticised for remaining within a positivist paradigm, and Charmaz aimed to develop a grounded theory method better suited to the interpretivist paradigm, and a social constructionist theoretical position. I therefore utilised the “systematic, yet flexible, guidelines” (Charmaz 2006:2) offered by this method. This is in line with the aim of positioning the young women as central to the research, and enabled a close and in-depth analysis of the data, and an exploration of the women’s perspectives as well as the influence of the social context in which they were embedded.

Feminism and intersectionality

Key feminist methodological and ethical principles were also integral to the research methodology. Feminist research aims to develop knowledge which is reflective of women’s own voices (Harding 1987; Oleson 2011; Hesse-Biber 2014), and positions women’s subjective meanings as central to understanding their experiences. It also seeks to understand the influence of social structure, such as gender relations and gender oppression, on women’s experiences and perceptions. A feminist position is complementary to social constructionist grounded theory given the emphasis on subjective experience, and the significance of social context. A feminist position also compels researchers to conduct reflexivity – to consider how the researchers’ position shaped the research and the research-participant relationship (Smith 1987; Oleson 2011; Hesse-Biber and Piatelli 2012). Adopting a feminist approach is consistent with the theoretical framework of this study, aiming to shed light on the ways that gendered constraints influence young women’s experiences and perceptions of living with a history of breast cancer (Kasper 1994; Thomas-MacLean 2005).

Intersectionality, as discussed earlier in the chapter, refers to the way that social divisions are interconnected with one another, and that this interconnection produces particular experiences (Crenshaw 1989; Collins 1998; Phoenix 2006, 2011; Yuval-Davies 2006). Intersectionality informs the methodological framework of this thesis with the aim of understanding how other social divisions, such as ageism, racism, and heterosexism, intersect with gender to inform young women's lives with a history of breast cancer. In order to be inclusive of two groups in particular who have been largely neglected in UK literature, I made the decision to purposively recruit young black and minority ethnic women, and sexual minority women.

Research design

The design of the research was informed by the methodological framework, and is introduced here. Greater detail about the methods employed is provided in Chapter Five.

Access and recruitment of participants

Access to participants was negotiated through gatekeeper organisations or snowballing (asking participants to pass on details to other women who met the study criteria), in order to contact potential participants via an organisation or person with whom they already had a relationship, given the sensitive nature of the research (Creswell 2007; Barbour 2014). A diverse group of organisations and support groups were selected to approach, and more information about these can be found in Chapter Five. This approach to accessing participants maintained a distance from the medical context, and was consistent with the focus of the research, which was on women's everyday lives.

The inclusion criteria for the study, developed from the literature review, were:

- Woman diagnosed with breast cancer while aged between 18-44
- Diagnosed at least twelve months previously, and within the last ten years

- Completed initial treatment in the UK
- Not currently receiving treatment for cancer, other than long-term preventative treatment such as Tamoxifen

A sample size of twenty was identified as optimal given the constraints on the researcher, and the aim of becoming immersed in the data. The age range was chosen because the age of 44 is well below 50, which is the age over which the majority (80%) of breast cancers are diagnosed. It is also well below the average age (50-51) of menopause (Hunter *et al.* 2011), increasing the likelihood of reaching a group of women who were pre-menopausal at diagnosis, an issue which the literature review indicated was significant.

Stakeholder panel

In order to engage young women in the research, I formed a stakeholder panel made up of three women who also fit the study criteria, and met with them three times over the course of the research. The aim of the panel was to engage women in the research, in line with feminist principles, so that the study was conducted *with* young women, rather than *on* them (Harding 1987, 2008; Kasper 1994; Smith 2007). It was also consistent with grounded theory, since the aim of grounded theory is to construct an understanding of the phenomenon which is recognisable to those people who actually experience it (Charmaz 2006). With the above in mind, at the first meeting we discussed the proposed information sheet and interview schedule, in order to think about any issues that I had not anticipated, and those which they felt would be most important. The second and third time we met involved discussions of the preliminary analysis and emerging findings of the study, and the resulting discussions have been drawn on in the findings chapters.

Data collection

Qualitative, semi-structured interviews were selected as the data collection tool for this research, as these were judged to be in line with the theoretical framework and the aims of the research. Semi-structured interviews gave women a level of freedom to choose how to tell their stories, consistent with feminist research methods (Cannon 1989; Alldred and Gillies 2008), but also enabled me to provide prompts and to further investigate areas identified as important through the literature review and preliminary analysis, consistent with grounded theory methods (Charmaz 2006).

Ethical issues

Ethical considerations were integral to the study, and approval for the study was granted by the Humanities and Social Sciences Research Ethics Committee (HSSREC) at the University of Warwick. I took the greatest care to remain sensitive and respectful towards interviewees, given the sensitive nature of the study, and consent was understood as a process (Ellis 2009). For example, topics which I judged to be particularly sensitive or difficult, such as the effect of breast cancer on their intimate relationships, were prefaced with a reminder that they were not obliged to talk about them. All potentially revealing data was changed or removed during transcription, and participants were assigned pseudonyms (Mason 2002). A more detailed discussion of the study's ethical implications, and how they were addressed, can be found in Chapter Five.

Data analysis

The data analysis was informed by Charmaz's (2006) guidelines for grounded theory methods of analysis, and involved three phases of coding data. Coding refers to "categorising segments of data with a short name that simultaneously summarises and accounts for each piece of data" (Charmaz 2006:43). Preliminary analysis in the form of initial coding was conducted concurrently with data collection. Initial coding was conducted

with the aim of summarising each segment in terms of processes, rather than applying pre-existing theoretical categories to it. Some segments were coded in the women's own words which enabled their understandings and perceptions to remain intact. After the initial phase, I conducted focused coding. This involved sorting and synthesising initial codes, and making decisions about which codes were the most useful, significant, and effective, in building an interpretation of the data. Finally, I focused the analysis by drawing on each element of the theoretical framework in turn, in order to explore in depth the women's accounts in relation to each research question.

Limitations of the research

There are several limitations to the research. For example, the small numbers of BME and lesbian women in the sample constitutes a limitation in terms of how far the findings from these women's accounts can be generalised. The use of semi-structured interviews for data collection relies on what the women remembered and what they were willing and able to talk about. However, this could be seen as a strength of the design, as the aim was to explore their perceptions. The use of one-off interviews means that the accounts are a snapshot of a particular time in the women's lives and illness trajectories. On the other hand, I was able to ask women to think back since their diagnosis, and to think about how they felt at different points. The coding practices which Charmaz (2006) suggests were variable in terms of their usefulness for this study. However, a strength of her version of grounded theory is that she presents them as flexible guidelines for practice, and I was thus able to experiment with different coding techniques.

Further discussion of all aspects of the theory of methodology and research methods used is provided in Chapter Five, including a critical reflection on my position within the research.

Thesis outline

Chapter Two – Embodiment and young women living with a history of breast cancer

Chapters two, three, and four contain the review of existing literature, and this review is organised by the theoretical framework. An account of the method of the literature review can be found in Appendix B.

Chapter Two reviews previous research in order to consider what it has suggested about the embodied experiences of young women living with a history of breast cancer and how they perceive these. It discusses theories of embodiment, and how they have informed this thesis, providing the theoretical context. It then reviews research about women's experiences of the impact of the physical effects of breast cancer treatment, young women's body image, and the significance of risk of recurrence for young women's experiences and perceptions of their bodies.

Chapter Three – Biographical disruption and young women living with a history of breast cancer

Chapter three discusses the theory of biographical disruption, considering critiques and developments of the theory, before exploring the potential of biographical disruption for understanding young women's experiences and perceptions of living with a history of breast cancer. In this chapter, I also discuss the concept of cancer survivorship, and investigate the current state of research about young women's perceptions the term 'cancer survivor' after breast cancer. Finally, the chapter explores the concept of liminality, and what previous research can tell us about the experience of liminality after breast cancer for young women.

Chapter Four – Gender and intersectionality and young women’s experiences and perceptions of breast cancer

The final chapter of the literature review evaluates existing research about the significance of gender and other intersecting forms of oppression in young women’s accounts of breast cancer. The chapter first explores with the ways that gender informs women’s experiences of breast cancer, including a discussion of emotion work. It then evaluates literature about how other social divisions, such as age, race, sexual orientation, and disability, inform the experience of breast cancer.

Chapter Five: Methodology and research design

This chapter describes and evaluates the methodological framework of the research, and the methods employed in the design and conduct of the study. It also discusses the ethical implications, and the limitations of the research.

Chapter Six: Young women at odds with their bodies: Embodied experiences and perceptions of living with a history of breast cancer

Chapters six, seven, and eight contain the findings of the research, reflecting the theoretical framework and research questions.

The first findings chapter explores the young women’s accounts of their embodied experiences, and how they perceived these. It first considers the significance of embodied risk in the young women’s accounts of their bodies after breast cancer, and the ways that this was related to their age and life stage at diagnosis. It also explores the dissonance which the young women encountered between their bodies and the expectations of their bodies held by themselves and others, as a result of breast cancer treatment. It finally analyses the accounts of the three women who were diagnosed while they were pregnant, considering how this shaped their experiences and perceptions of their bodies.

Chapter Seven: The significance of biographical disruption in young women's accounts of living with a history of breast cancer

In this chapter, I explore the extent to which biographical disruption characterised the young women's accounts. I also investigate the young women's responses to the term breast cancer survivor, and map the ways that uncertainty was connected to the young women's age and life stage at diagnosis. The chapter also discusses the impact of breast cancer on young women's life course, and personal relationships.

Chapter Eight: Young women's accounts of the impact of gender and its intersection with other social divisions

Chapter Eight explores the significance of gender and intersectionality in the young women's accounts. It first considers the impact of gendered ideals about the body, fertility and motherhood, and also the performance of emotion work. It then discusses the significance of ageism, before exploring the accounts of the black and minority ethnic women, the two women who identified as lesbians, and the two disabled women in the study, considering how their particular social positions shaped their perspectives during and beyond treatment. It finally considers the financial impact of breast cancer for the young women.

Chapter Nine: "It just literally pulls you apart in every direction". Combining the three analytical dimensions of the theoretical framework

This short chapter draws on all three dimensions of the theoretical framework in order to demonstrate the profound impact of breast cancer on the lives of young women with a history of breast cancer, and highlights the ways that the three dimensions overlapped in the young women's accounts.

Chapter Ten – Conclusion

In this final chapter, I briefly review the theoretical framework, methodology, and limitations of the research, before setting out the key findings of the research, and identifying areas for further exploration.

Chapter Two – Embodiment and young women living with a history of breast cancer

Introduction

Theories of embodiment position the body as central to human experience. Rather than being an object which is acted upon by the external world, the body is constitutive of everyday experience; the grounds of experience itself. The diagnosis and treatment of a disease such as breast cancer has profound effects on a young woman's body and, therefore, on her experiences and perceptions. Lupton writes of a theory of embodiment which incorporates both phenomenological and social constructionist theories: "experiences such as illness, disease, disability and pain exist as biological realities, but...such experiences are always inevitably given meaning and therefore always understood and experienced through cultural and social processes" (2012:11). Influenced by this approach, in this thesis I explore young women's experiences of their body as constitutive of everyday experience, and the way that this occurred within a social context. There is a danger of reducing experience to biological and physical processes; however, a theory of embodiment as described by Lupton (2012) above, seeks to situate embodied experiences within their social context.

In this chapter I first discuss theories of embodiment, and how these inform this thesis, specifically phenomenological, social constructionist, and feminist theories of the body. I then examine existing research about breast cancer, focusing first on physiological changes caused by breast cancer in the following areas: mastectomy, sensation and physicality, treatment-induced menopause and fertility, and sexuality. The impact on impact on young women's body image is then considered, drawing on a definition of body image which goes beyond (dis)satisfaction with the body. The final section explores the concept of embodied

risk, considering existing research about the fear of cancer recurrence and embodied reminders. This critical evaluation identifies the ways that existing research can be built upon in order to expand understanding of young women's lives after breast cancer.

Theories of embodiment and the theoretical context for the study

In this section, I discuss three approaches to theorising the body: social constructionist, phenomenological, and feminist approaches. These overlap in a number of ways, but it is useful to draw distinctions to understand the way that the body has been conceptualised in sociological work, and to explore the tensions within sociological work on embodiment. This will provide the context for this dimension of the theoretical framework.

Social constructionists have explored the ways that bodies are constructed through social processes, and how illness is experienced in a given social context, rather than only biologically (Turner 1984; Lupton 2012). For example, the concept of 'medicalisation' has been used to draw attention to the way that doctors are assigned the authority to determine who is considered ill (Freidson 1970; Illich 1976). Social constructionist approaches have been criticised for neglecting physiological processes and bodily experiences, emphasising instead social representations of the body, and meanings assigned to physical processes (Williams and Bendelow 1998; Williams 2006). In order to combat this accusation of reductionism, social constructionists, such as Turner (1992, 2009), have drawn on phenomenological approaches to the body to develop a perspective which acknowledges the materiality of the body, as well as the way it is socially constructed within a given socio-cultural context.

A phenomenological perspective on embodiment emphasises that a person's engagement with the world occurs through their bodies (Van Manen 1990). The philosopher Merleau-Ponty (1945/2012) saw the body as inevitably intertwined with its setting. He proposed the notion of the 'body-subject', arguing that humans are not simply minds who possess bodies,

but that the body is the grounds of experience and is constitutive of being in the world. Therefore, the experience of illness shapes how an individual experiences the world, because of the impact of illness on the body. For example, illness might be experienced as a betrayal, resulting in distrust of and alienation from the body (Williams 1996). A phenomenological approach makes the body central to experience, but it has been criticised for its limited ability to provide an account of power and social relations (Howson and Inglis 2001). For example, it has been argued that theorists of embodiment, such as Grosz (1995), tend to divorce the body from its social and biographical context, resulting in an abstract body, devoid of social or cultural meaning (Jackson and Scott 2001). Phenomenological theorists of the body, including Merleau-Ponty, have also been criticised for a lack of engagement with the significance of gender in understanding people's embodied experiences (Lupton 2012).

Feminist scholars of the body have drawn attention to the relationship between gender relations and bodily experiences. Some feminists have argued that the biological differences between men and women have historically been exaggerated to justify the oppression of women, whereas others have explored the particular embodied experiences of women (Ehrenreich and English 1977; Lupton 2012). Some feminist scholars have drawn on both social constructionist and phenomenological approaches. For example, Young (2005) explored women's unique bodily experiences, such as being pregnant or breastfeeding, to demonstrate commonalities of female experience and the differences between men and women, but also the ways that cultural meanings of such phenomena shape women's experiences of them. Feminist theories of embodiment have aided understanding of the influence of social position and how cultural forces shape people's individual experiences of their bodies, while also addressing the embodied nature of life.

There has thus been a tension within the sociology of the body because, on the one hand, theorists and researchers drawing on phenomenology place the focus on the material and

corporeal elements of the body, yet on the other hand, a sociological perspective necessitates attention to social structure and the way that such embodied experience is situated, understood, and represented in a given social context (Howson and Inglis 2001). Scholars such as Williams (2006) and Lupton (2012) have argued for an understanding of the body which draws on socio-cultural constructions of the body, and which also takes into account the materiality of the body.

This chapter demonstrates that an approach to embodiment which draws on both social constructionist and phenomenological theoretical perspectives, such as that outlined by Lupton (2012), may deepen understanding of young women's lives with and beyond breast cancer. Such an approach acknowledges the significance of the materiality of the body for young women with a history of breast cancer, as well as the particular social context in which the experience occurs. I now turn to existing research about women living with a history of breast cancer, in order to review what this literature has revealed about young women's embodied experiences and perceptions of living with a history of breast cancer, and to identify avenues for further investigation. I begin with a discussion of the impact of physiological changes caused by breast cancer treatment.

Physical effects of breast cancer treatment

Mastectomy

Much research which has explored the embodied experience of breast cancer has focused on breast loss and the impact of mastectomy (e.g. Langellier and Sullivan 1998; Bredin 1999; Piot-Ziegler *et al.* 2010 ; Fallbjork *et al.* 2012). Breast conserving surgery, also known as a lumpectomy, involves removing the cancerous cells rather than the entire breast, and a certain margin clear of cancerous cells is required for this to be considered successful (NICE 2013). The national average ratio of mastectomies (MX) to breast conserving surgeries (BCS) carried out in the UK is 1:1.3 – a slightly higher rate of breast conserving surgeries to

mastectomies (Lawrence *et al.* 2011). However, when examined by age group, the results demonstrated that women under 40 were significantly more likely to have a mastectomy (MX:BCS ratio 1:0.8) than those aged 50-69 (MX:BCS ratio 1:1.8). Despite this, there is little evidence in the literature about how the life stage of a woman at treatment shapes her experience of mastectomy.

Research about the experience of mastectomy has established that it can result in altered bodily perceptions for women. For example, Piot-Ziegler *et al.* (2010, SU), conducted interviews with 19 women aged 37-62 (mean age 48) about the effects of mastectomy on their feelings about their body. They found that women went through a process of comprehending their breast as wounded and ill, and the breast came to symbolise cancer and grief. Similarly, Burles' (2010, CA) research found that the three young women (aged under 40) in her study with a history of breast cancer experienced their breasts as a source of anxiety, rather than of sexuality. Existing research has also identified the experience of breast loss as a loss of femininity, which is discussed in more detail in Chapter Four.

Some research has also explored how the responses, or anticipated responses, of others to their breast loss shape women's perceptions of breast loss. For example, Thomas-MacLean (2005, CA) found that the twelve women (aged 42-77) women in her study, conducted practices of concealing and manipulating their appearance in order to present a body which appeared normal despite mastectomy. These practices resulted in everyday activities, such as getting dressed, taking on new meanings. She found that women experienced their bodies with mastectomies as unpredictable. For example, they feared their prostheses falling out and the negative responses which this would elicit from others.

Swedish researchers Fallbjork *et al.* (2012, SW) identified three themes in the accounts of the fifteen women in their study (aged 39-69), and found that the mean age of the women in each narrative differed. The narrative of the group which included all three of the women

under 45 at diagnosis, and a mean age of 47 was identified as ‘wounded femininity’. In this theme, breast reconstruction was seen as a way of restoring a lost femininity, and disguising breast loss. The oldest group (mean age 60) viewed the lost breast as having performed its function in life. Femininity was less associated with breasts and more with choice of dress and behaviour. This perception was described by the women themselves as being related to their older age. This indicates that younger and older women may hold different perceptions about breast loss as a result of their age, but this should not be over-generalised given the small numbers (three) of young women in their study.

In the UK, younger women are more likely to undergo immediate breast reconstruction amongst women who have a mastectomy (Jeevan *et al.* 2010; Lawrence *et al.* 2011). 26% of women under the age of 40 who had a mastectomy had immediate reconstruction, compared to 17% of women aged 50-59 (Lawrence *et al.* 2011). Connell argued that concerns about appearance may be more salient for younger women due to high expectations placed on them related to youth and attractiveness (Connell 2005, AU). As Helms *et al.* (2008) noted, many women are already worried about their appearance, and women who have been treated for breast cancer may have the same body image concerns as they did previously, only they now also have a changed body to negotiate. However, this discussion remains focused on bodily experience as related to appearance, which is clearly important, but neglects the issue of sensation and physicality.

Sensation and physicality

It has been argued that research from a feminist perspective might privilege an exploration of the impact of breast surgery on sensation rather than on appearance (Thomas-MacLean 2005). For example, surgery to the lymph nodes can cause numbness in the armpit, and surgery and reconstruction can result in numbness in the breast or chest area, and loss of muscle strength (Ashing-Giwa *et al.* 2004).

The women in Thomas-MacLean's (2005) study described the sensations which resulted from treatment. One woman said "[i]f I touch the skin where the nipple was, the sensation is the same as if it was still there" (p.203). Thomas-MacLean argued that, as a result of these physical and tactile changes, the women went through a process of having to learn about their changed bodies, such as how to apply deodorant to an armpit which is completely numb. Other research has also indicated the impact on physicality. For example, Langellier and Sullivan's (1998, US) study found that the twenty women interviewed (aged 32-64) talked about the impact of breast loss in terms of causing disruption to their mobility and ability to carry out physical activity, such as gardening. A woman in Piot-Ziegler *et al.*'s (2010) study described her sense of being unbalanced due to her mastectomy and remaining breast. Women may find that they feel a sense of physical asymmetry in terms of sensation as well as appearance.

The studies by Piot-Ziegler *et al.* (2010) and Langellier and Sullivan (1998), both focused on breasts and mastectomy, rather than on the broader impact of treatment on women's sensations in their bodies. The impact of treatment-induced menopausal symptoms, such as aching and painful joints, may have particular implications for young women in terms of affecting mobility and physical activity. There is existing research exploring women's broader concerns about treatment-induced menopause (e.g. Anderson *et al.* 2011; Thewes *et al.* 2003), and this is discussed further below, but its impact on sensation and physicality has not been explored. Drawing on embodiment and focusing on sensation and physicality could assist in understanding how young women experience their bodies as changed in their everyday lives, beyond the impact of mastectomy and reconstruction.

Treatment-induced menopause and fertility

The average age of menopause in the UK is 52 (NICE 2013), thus the majority of women under 45 will be pre-menopausal at diagnosis. Many young women will experience

menopausal symptoms as a result of breast cancer treatment, although these may not indicate a permanent menopause or loss of fertility (Anderson *et al.* 2011).

It has been found in both qualitative and quantitative studies that younger women with breast cancer have support and information needs with regards to fertility (e.g. Dunn and Steginga 2000, AU; Thewes *et al.* 2003, AU; Avis *et al.* 2004, US; Gould *et al.* 2006, CA; Coyne and Borbasi 2007, AU; Kirkman *et al.* 2014, AU). For example, Partridge *et al.* (2004) found in their US survey of women with a history of breast cancer, that 73% of women before the age of 40 were concerned about their fertility status. Lee *et al.* (2011, UK), conducted focus groups with 24 women diagnosed with breast cancer before age 40, with the aim of exploring their thoughts and feelings about the effects of treatment on fertility and their experience with health services in relation to fertility. For most women, survival was their main priority, but women without children were prepared to take more risks in order to preserve their fertility. Lee *et al.* focused on the decisions made by women at the time of diagnosis and treatment, rather than the impact of fertility on the everyday embodied experiences and perceptions of young women.

A recent study (Kirkman *et al.* 2014, AU) involved ten women aged 26-45, and explored the young women's reflections on fertility and motherhood after initial treatment for breast cancer. The authors demonstrated that the young women found that their bodies were suddenly changed in terms of appearance and also in how their bodies functioned. Previously taken-for-granted ideas about their bodies, such as its ability to conceive and to breastfeed had been challenged, and women lost confidence in their bodies as fertile. Research has also identified that women with a history of breast cancer experience the loss of fertility and menstruation as a loss of femininity and womanhood (Klaeson and Bertero 2008; Kirkman *et al.* 2014), discussed further in Chapter Four. The women in Klaeson and Bertero's (2008, SW) study found that they now dressed differently as a result of the changes to their bodies caused by treatment-induced menopause, indicating the impact on

the women's everyday lives. Wilmoth (2001, US) points out that some of the feelings about menopause that young women express are similar to those that every woman may experience as she approaches menopause. The difference is that treatment-induced menopause happens rapidly, and at a life stage not normally associated with menopausal symptoms. A woman in this situation must confront not only the life-threatening nature of breast cancer and its visible changes, but also the sudden and unexpected experience of a menopausal body.

Breast cancer is the most common cancer associated with pregnancy (Connell 2005), and, according to Cancer Research UK (2014c), breast cancer is diagnosed in 1 in 3,000 pregnancies. Women may undergo breast surgery when pregnant, and chemotherapy can also be given if the pregnancy has reached the second or third trimester, although radiotherapy is not given until after the birth (Brennan *et al.* 2005). However, there is almost no evidence about young women's experiences of this. One woman in Burles's (2010) study found symptoms of breast cancer during her pregnancy but was told by medical professionals that it was not breast cancer. She had to push for it to be investigated, trusting in her bodily experiences over the advice of health professionals. Another woman in Kirkman *et al.*'s (2014) study was diagnosed early in her pregnancy, and decided to terminate the pregnancy so that treatment could commence. This woman's account demonstrated that she felt she needed to justify her decision to have an abortion, but the authors did not explore the particular bodily experiences and perceptions which may have arisen from this experience. The embodied experiences of what it is like to be diagnosed with breast cancer while pregnant have therefore not been thoroughly explored, and this is a phenomenon which only young women can experience.

Sexuality

Existing research has found that the problems arising from breast cancer treatment which impact on sexuality and sexual functioning are often described by women of all ages as the worst effect of treatment (Wilmoth 2001; Archibald *et al.* 2006; Gilbert *et al.* 2010), and a review of the literature found chemotherapy to be the most important factor in determining sexual problems after breast cancer (Gilbert *et al.* 2010). Researchers, such as Gilbert *et al.* (2010), have argued that the configuration of women's personal and social context is significant in understanding her experience of sexuality after breast cancer:

“The physical body cannot be conceptualised independently from women's...relational context, and the discursive constructions of sexuality and femininity in a particular socio-cultural context” (2010:405-406).

A recent Dutch study (Kedde *et al.* 2013) used quantitative measures to explore young women's sexual well-being, finding that young women living beyond initial treatment had similar amounts of sexual activity to the general population, but that there were differences in terms of how they experienced sex. In particular, women who found it difficult to discuss sexuality with their partners had negative experiences.

For younger women, the impact on sex may also be connected to other factors, such as concerns about fertility, and the onset of premature menopause. Anderson *et al.* (2011, AU) compared the experiences of six women diagnosed under age 40 (aged 34-36), with those of ten women diagnosed over 40 (aged 42-53), finding that women from both groups described the impact on sex as the most difficult aspect. The younger group of women experienced profound distress because their symptoms resulted from treatment-induced menopause, and they felt isolated because their peers were not having similar experiences, yet the literature provided to them was aimed at older women. These symptoms included vaginal dryness and

resulting pain during intercourse, and a loss of interest in sex. The women desired more information about this issue.

Swedish researchers Klaeson and Bertero (2008) interviewed six women (aged 38-48), who had become menopausal as a result of breast cancer treatment, about the impact on their sexual identity. They found that the women's perceptions of their sexual identities were dramatically changed, and they felt constrained because of the impact of treatment on their bodies and their sexuality. One woman felt that she had "withdrawn" from her husband because she felt "disgusted" with her body after breast cancer (p.190). There remain questions about the significance of the women's personal and biographical context in this small study. For example, the authors did not distinguish if the women were permanently menopausal, or whether this made a difference to how they understood their sexual identity after breast cancer. Nor do the authors identify if the participants had planned to have (more) children when they were diagnosed, and how or if this was related to their experiences of their sexual identity.

Little research has explored positive sexual changes after breast cancer. Archibald *et al.* (2006, CA) specifically asked thirty women (aged 31-57) about positive sexual experiences after chemotherapy-induced menopause, finding that some of their participants reported positive changes. These were often related to the increased emotional closeness with their partner after the experience of cancer, and the ability of their partner to be patient and understanding, again emphasising the importance of a woman's personal circumstances. Sexual functioning was seen as a meaningful part of their lives, but women in Anderson *et al.*'s (2011, AU) research felt that their doctors were dismissive of the sexual side-effects which they reported. Although 13% of the women in Archibald *et al.*'s study were single at the time of interview, the significance of this in their accounts of their sexual experiences after breast cancer is not discussed. Archibald *et al.*'s study also revealed the nuanced and variable ways in which women experienced sexual problems. For example, decreased sexual

arousal for some women meant a total lack of sensation, whereas for others it meant it took longer for them to become aroused.

This section has explored existing research on the impact of the physical effects of treatment on young women's everyday bodily experiences. The analysis of the literature suggests that breast surgery has a significant impact on women's lives, but that a feminist analysis may wish to explore beyond mastectomy and reconstruction, to explore how other physical effects may impact on how women experience and perceive their bodies. Young women may experience a suddenly menopausal body, and this shapes their everyday lives and perspectives on their bodies. Little research has explored the experience of being diagnosed during pregnancy. The existing research illustrates the importance of sexual changes after breast cancer in young women's lives, and also the significance of women's personal and social circumstances.

Body image

Breast cancer treatment may alter a woman's body image. Body image can be viewed as more than (dis)satisfaction with appearance, but also as a sense of bodily coherence or wholeness (Bredin 1999, Brunet *et al.* 2013). Schilder (1950) defined body image as "the picture of our own body that we form in our mind... We have tactile, thermal, pain impressions... The immediate experience that there is a unity of the body..." (cited in Williams and Bendelow 1998:98). Schilder's definition incorporates the appearance of the surface of the body, but also the sensation of the inner workings of the body, the tactile senses of the body, and a feeling of continuity of the body. This indicates the subjective experience of body image, and the way that one's body image may be unrelated to the ways that the body appears to others.

Some studies about the experiences of young women with breast cancer have taken a relatively narrow approach to body image, focusing on (dis)satisfaction with one's body, or

using quality of life ‘body image problems’ scales (e.g. Bloom *et al.* 2004, US).

Approaching body image in this way produces a false dichotomy of body image as being either positive or negative, rather than exploring the multiple dimensions of living with and within a body which has been treated for a life-threatening illness (Fallowfield *et al.* 1991; White 2000; Brunet *et al.* 2013). In addition, research on body image and breast cancer has been criticised for focusing on breast removal, conservation and reconstruction (Brunet *et al.* 2013). Brunet *et al.* (2013, CA) argue for a multidimensional approach to body image in order to take into account the complex and socially situated experiences of women in relation to their body after breast cancer treatment. There may also be conflicting dimensions of embodiment. For example, while breast conserving surgery such as lumpectomies may have better results for women in terms of their satisfaction with their appearance, it may have worse effects than mastectomy in terms of anxiety about recurrence (Bredin 1999).

Schilder’s definition also acknowledges that body image is experienced in relation to ideas about how others perceive one’s body (Williams and Bendelow 1998). Research illustrates how visible bodily changes induced by breast cancer treatment are experienced by women in social interactions with others. For example, in many studies about the experience of breast cancer, women cite hair loss as a worse experience than breast loss (Wilmoth 2001; McCann *et al.* 2010; Tighe *et al.* 2011; Trusson 2013). The reasons often cited for this is that the public nature of hair loss makes it more difficult to hide from others, that hair loss is heavily associated with cancer, and that there is a perceived stigma associated with signifying ‘cancer patient’ through one’s body (Mathieson and Barrie 1998). Not all chemotherapy regimens have the same effects, but those used in the treatment of breast cancer do tend to cause total alopecia (Hunt and McHale 2005). Although hair loss through chemotherapy is usually temporary, hair may grow back a different texture, thickness or colour (Harcourt and Frith 2008), increasing the long-term outward changes which women may perceive as indicating their status as ‘person with cancer’. Hair loss is a particularly visible cue and is

often cited by women as the most difficult part of treatment, which goes some way to explaining why it has received a lot of attention from researchers. However, the significance of invisible bodily changes in young women's accounts of their interactions with others has not been explored. For example, women may experience chronic pain after surgery and radiation therapy (Macdonald *et al.* 2005), and they may suffer from stiff joints due to treatment-induced menopause (Bloom *et al.* 2004). Some studies suggest that women experience long-term changes to their cognitive ability, such as memory loss or difficulty concentrating (Avis *et al.* 2004; Thomas-MacLean 2005; Tighe *et al.* 2011). These long-term effects are not visible to others, but they are likely to shape how young women experience their bodies in everyday interactions with others.

Brunet *et al.* (2013) also argued that research about breast cancer has not explored positive bodily experiences of women after treatment, focusing either on the negative experiences, or on positive identity shifts and transformations of perspectives on life. Brunet *et al.* found that four of the eleven women (aged 47-70) in their study expressed positive feelings about their body, referring to it as brave or strong. These positive body experiences reflected aspects of their body beyond its appearance, and some women felt a new appreciation for their body.

An approach which considers body image to be more than only the evaluation of one's body, therefore, facilitates a broader and deeper exploration of how women experience their bodies after breast cancer which goes beyond (dis)satisfaction with the body, and the impact of breast surgery. Further, it can enable an exploration of the way that young women experience their bodies in relation to others. Previous research has focused on hair loss, but there may be other visible, or invisible, physical changes which shape young women's experiences and perceptions of their bodies in social interactions. The positive bodily experiences which young women may have after breast cancer are also under-researched.

Embodied risk

Recent research about how individuals experience and perceive risks in their everyday lives has indicated that people draw on their own biographical and experiential knowledge, as well as expert knowledge when making sense of health risks (Lupton 2012; Hesse-Biber 2014). Some research, discussed in this section, has also explored how health risk is experienced through the body (Kavanagh and Broom 1998; Robertson 2000), highlighting how a perspective which explores embodiment may be useful for understanding how young women experience and perceive the fear and risk of breast cancer recurrence.

Australian researchers, Kavanagh and Broom (1998), conducted in-depth interviews with 29 women (aged 29-70) who had an abnormal cervical smear in order to explore how the women understood their risk, finding that the women experienced ‘embodied’ or ‘corporeal’ risk. They argued that, while social scientists have focused on environmental or lifestyle risks, embodied risk is a third type of risk which individuals experience. In this third type, the risk is located not in external surroundings (environmental), or in the behaviours or decisions (lifestyle) of individuals, but within individuals’ own bodies (although it can also overlap and interact with environmental and lifestyle risk). The women in Kavanagh and Broom’s study found that they experienced their bodies as inherently risky, and the annual smear tests were acts of surveillance through which “the body [was] continually produced as a source of danger” to the women (p.440). This resulted in a sense of alienation from the body, as it was seen as a threat and as unpredictable. Robertson (2000) interviewed twenty Canadian women (aged between 30 and 50) who had not had breast cancer but had attended a breast health clinic for screening or information. She found that these women, in particular those with a family history, experienced embodied risk, perceiving their breasts to be ‘treacherous body parts’ (p.223), or ‘time bombs’ (p.225).

Embodied reminders

Illness can cause a person to become aware of their body in new ways, as the body becomes a central aspect of experience during illness, and this can also be understood as a loss of control and alienation from the body (Turner 1984; Williams 1996). The body becomes problematic, and this can continue on after treatment for breast cancer. For example, research suggests that long-term changes such as scarring, and the daily Tamoxifen tablet, are experienced by women as reminders that they had breast cancer, and may prevent women from feeling that they have returned to normal. Bredin (1999, UK) argued that distress about bodily changes may not become evident until months after treatment, when life is expected to return to normal. Women in research talk about being able to forget about breast cancer while fully clothed, but experiencing a reminder whenever they get undressed and see their changed bodies (Wilmoth 2001; McCann *et al.* 2010; Fallbjork *et al.* 2012). A woman in McCann *et al.*'s (2010:1973) study referred to the Tamoxifen as the daily “cancer tablet”, and another in Brunet *et al.*'s (2013:347) study as something which had “high-jacked” her body. Archibald *et al.* (2006) found that women who were pre-menopausal before breast cancer often viewed a return to normal sexual functioning as a pivotal experience, symbolic of their life returning to normal. This illustrates how ‘normality’ is not simply the end of treatment, but is also something which is felt through the body, perhaps in unexpected ways.

The long-term changes and the ongoing hormonal treatment may prevent women from feeling normal, and act as embodied reminders. The physical changes which women experience after breast cancer may blur the boundaries of ‘ill’ and ‘healthy’ (Frank 2002; Bell and Ristovski-Slijepcevic 2013), and alter the embodied experiences and perceptions of women living with a history of breast cancer. Women find that the body and its health can no longer be taken for granted, and reminders of the cancer are experienced through the body.

Fear of cancer recurrence and embodied risk

Embodied risk has not been explored in studies with women who have a personal history of breast cancer, and the ways that age might influence the experience of embodied or corporeal risk in terms of fears about recurrence has also not been explored. Research indicates that women may develop a distrust of their body after breast cancer, perceiving everyday aches, pains, and coughs, not only as reminders of cancer, but also as evidence of cancer recurrence (Thewes *et al.* 2004; Lindwall and Bergbom 2009). Research with young people with cancer and other illnesses has found that, after diagnosis, the body becomes a threat, and illness generates feelings of distrust, betrayal, and confusion, towards the body, because it contradicts their experience of their bodies as young adults (Snobohm *et al.* 2010; Burles 2010).

Living beyond breast cancer as a young woman raises complex and distinctive issues regarding risk and fears about recurrence. Women who are receiving preventative hormonal treatment must balance the impact of its side-effects on their everyday lives with the potential for recurrence. For example, some women in McCann *et al.*'s (2010, UK) study spoke about wanting to end the hormonal medication because of the impact the side-effects were having on their daily lives, and they felt that quality of life was more important than length of life. The sense of feeling prematurely aged by treatment because of treatment-induced menopause was seen as worse by some women in the study than the possibility of recurrence.

One way in which women may choose to combat their risk is through contra-lateral prophylactic mastectomy (CPM), which is a radical surgery involving the removal of a healthy breast in order to prevent a future diagnosis of breast cancer in that breast. Recent statistics from the USA suggest that increasing numbers of women at average risk of breast cancer are choosing CPM as a preventative measure (Yao *et al.* 2010). The rates of CPM in

the UK have not yet been properly assessed, but Murphy *et al.* (2013) argue that we can expect the trend to be reflected in the UK given that approaches to treating patients at risk of breast cancer historically have tended to converge with the US. Between 2 and 11% of women diagnosed with breast cancer will develop contralateral breast cancer, and women who have had breast cancer are between two and six times more likely to develop contralateral breast cancer than women in the general population are likely to develop a primary breast cancer (Chen *et al.* 1999), and the risk is much higher if a woman has a BRCA1/2 mutation. However, the impact of CPM on survival rates is very small; one study found it to be less than 1% (Portschy *et al.* 2014).

Lostumbo *et al.* (2010) pointed out that there is emerging a paradox in the surgical management of breast cancer whereby conservation surgery (lumpectomy) has become more common for the treatment of diagnosed cancer, while the more radical treatment of mastectomy is increasing in the prevention of a potential cancer. Lumpectomy is seen as the more favourable option because it involves the removal of less tissue and, it is argued, less distress related to aesthetic appearance after treatment (Lostumbo *et al.* 2010), and mortality rates are not significantly increased for many types of early stage breast cancers when radiotherapy is also given (Paszat *et al.* 2000). Mastectomy cannot provide a complete reduction of risk of breast cancer since it is possible that cancer cells can remain in tissue in the chest wall (Lloyd *et al.* 2000). In addition, there is the possibility of complications from mastectomy surgery such as numbness of the chest skin, chronic pain, and loss or impairment of arm strength and mobility. A recent study surveying women with a history of breast cancer under age 40 who had chosen to have CPM found that lowering risk, peace of mind, and improving survival chances were ranked as extremely or very important by 94-98% of participants, while the aesthetic appearance of the breasts was ranked as extremely or very important by 27-31% of the participants (Rosenberg *et al.* 2013). Studies have found that younger women are more likely to opt for CPM (e.g. Tuttle *et al.* 2009; King *et al.* 2011; Jones *et al.* 2009; Yao *et al.* 2010), and Mehnert *et al.* (2009)

found that fear of cancer recurrence was highest among younger women, but these studies have not explored the meaning of CPM from the perspectives of young women with a history of breast cancer, nor considered how embodied risk may be significant in understanding this.

Earlier in this chapter, I discussed literature about women's concerns related to infertility. A less well researched phenomenon is that of regained fertility (Connell *et al.* 2006). There are particular challenges related to negotiating regained fertility, and these are related to how young women experience and perceive their bodies after breast cancer, and their fears about recurrence. For example, Connell *et al.* (2006, AU), found that young women had anxieties about the use of hormonal contraception because of its link with breast cancer, but they were also wary of becoming pregnant because they felt that this might increase their risk of recurrence. Connell *et al.* also found that women were concerned that pregnancy and breastfeeding made it more difficult to detect changes in their breasts. Women are advised not to become pregnant in the first two years after treatment because this is the period during which most recurrences occur (Brennan *et al.* 2005), but the scientific consensus is that pregnancy after breast cancer does not impact on the breast cancer mortality rate (Azim *et al.* 2011). Research has also found that young women fear passing on a genetic susceptibility to children (Siegel *et al.* 1997; Kirkman *et al.* 2014), and that this shapes their decisions about pregnancy after breast cancer. Young women who have breast cancer are more likely than older women to have a family history, and to have a BRCA gene mutation (Brennan *et al.* 2005). Further research drawing on theories of embodiment could explore how young women negotiate the challenges of regained fertility in their everyday lives, and how this informs their perceptions of their bodies.

Conclusion

This chapter has profiled theories of embodiment, demonstrating that an approach which incorporates both social constructionism and phenomenology informs this thesis. A

perspective which positions the body as constitutive of experience, but also acknowledges that illness is not only experienced physically, but also socially, may be useful in deepening understanding of young women's lives after breast cancer.

Body image can be understood as more than only the evaluation of one's body, and research on body image after breast cancer has thus been criticised for a tendency not to go beyond studying women's (dis)satisfaction with their bodies, and the impact of breast surgery.

Drawing on the perspective of embodiment outlined above, may enrich the understanding of the physical effects of treatment on women's everyday lives. By exploring the impact on sensation and physicality, the experience of having to contend with a suddenly menopausal body at time when peers are not having similar experiences, and the social and personal context of the physical effects on sexuality, the everyday embodied experiences of young women living with a history of breast cancer may be illuminated. Understanding of young women's experiences of living beyond breast cancer treatment, and the complexities of negotiating regained fertility, may also be expanded through exploring embodied risk, a type of risk which individuals may experience when the source of the risk is perceived to be located within their own body.

In this chapter I have situated this research within the context of theories of embodiment and empirical research about women's experiences and perceptions of living with a history of breast cancer. An approach to embodiment which draws on both phenomenological and social constructionist conceptualisations of the body will be utilised in this research. I have argued that existing research has not drawn out the distinctive embodied experiences and perceptions of young women with a history of breast cancer, and identified several areas which can be built upon or explored. I now turn to the significance of biographical disruption in previous research about young women living with a history of breast cancer.

Chapter Three – Biographical disruption and young women living with a history of breast cancer

Introduction

In this chapter, I discuss the theoretical framework of biographical disruption and explore its relevance in analysing and understanding the experiences of young women living with a history of breast cancer. The onset of a chronic or serious illness may be experienced as biographical disruption, in which a person's previously taken-for-granted assumptions about everyday life, relationships and the future are challenged (Bury 1982). Biographical disruption may therefore characterise the experiences and perceptions of young women living with a history of breast cancer, and presents a useful framework for analysing and understanding young women's accounts. However, the theory of biographical disruption has been critiqued in the decades since Bury first conceptualised it, and a critical approach to the theory is therefore adopted in this thesis. For example, researchers (such as Pound *et al.* 1998; Ciambrone 2001; Williams 2003; Wilson 2007) have challenged the idea that illness is always biographically disruptive, and highlighted the importance of biographical and social circumstances in the experience of illness. In this chapter, I also discuss the concept of cancer survivorship, and the extent to which it may be drawn upon by young women with a history of breast cancer when making sense of their experience (Little *et al.* 2002; McKenzie and Crouch 2004; Kaiser 2008; Khan *et al.* 2012b; Pertl *et al.* 2014; Stephenson *et al.* 2013). I also discuss the concept of liminality, which may have potential to explain the experiences of young women living post-treatment for breast cancer, taking into account that they may not feel 'healthy' yet not 'ill' (Little *et al.* 1998; Navon and Morag 2004; Cayless *et al.* 2009; Hubbard and Forbat 2012; Trusson 2013).

I first set out the concept of biographical disruption as formulated by Bury (1982), followed by a section which evaluates the significance of critiques of the theory, in particular those which have drawn attention to the significance of the personal and social circumstances in which illness occurs. I then discuss research about biographical disruption and cancer in the light of these theoretical developments. Following this, I explore the concept of cancer survivorship, and evaluate research about the perceptions of the survivor label held by those to whom it might be applied. In the final section, I introduce the concept of liminality as developed by Little *et al.* (1998) in relation to the experience of cancer, and explore how the concept may be useful in understanding young women's experiences of living with a history of breast cancer.

Illness as biographical disruption

The idea of illness as biographical disruption was initially conceptualised by Bury (1982), who proposed that the onset of chronic illness causes major disruption to the structures of everyday life, and the taken-for-granted assumptions underpinning them. In his study about the experiences of thirty individuals newly diagnosed with rheumatoid arthritis, he identified three aspects of disruption. First, the experience of disruption to previously taken-for-granted assumptions and behaviours, which “involves attention to bodily states not usually brought into consciousness” (Williams 2003:96), as people experience physical symptoms. Secondly, there were disruptions to explanatory systems normally used; “such that a fundamental re-thinking of the person's biography and self-concept is involved” (Bury 1982:169). The person asks questions such as ‘Why me?’, ‘Why now?’, and attempts to understand the illness in the context of their lives. The third aspect identified by Bury was that of the individual's response to the disruption, involving the mobilisation of resources in the face of an altered situation.

The framework developed initially by Bury, therefore, provides an analytical framework for examining how people experience chronic illness, and the work involved in constructing, re-

constructing, and maintaining their identity in the face of illness. Bury's work has proved to be an influential and persistent theory in the decades since it was published (Williams 2003). It offers a critique of the biomedical emphasis on recovery and restitution after illness, and can be seen as a conceptual starting point to begin analysis of the experience of illness. However, several weaknesses have been identified, and this has led to developments of the theory. For example, it arguably supports a 'personal tragedy' model of disability (Williams 2003:99), which views disability as a characteristic located within individuals rather than as culturally and socially produced through practices which result in the oppression and social exclusion of disabled people (Shakespeare 2006). Within Bury's framework, the significance of socially constructed ideas about disability or illness was overlooked. Critiques of Bury's (1982) work have thus often questioned how well it engaged with how social inequality and social structure shape the experience and perception of illness. The following section engages with other recent developments of the theory of biographical disruption, and identifies their relevance to this study

The significance of biographical and social circumstances

Social constructions about age and the life course have been shown to shape the experience of illness. For example, Bury (1982) identified that the younger women in his study held perceptions about rheumatoid arthritis as a disease of the elderly, and their diagnosis therefore made them question their identities as young people. The illness was experienced as a "biographical shift from a perceived normal trajectory through relatively predictable chronological steps, to one fundamentally abnormal and inwardly damaging" (1982:171). On the other hand, illness may be experienced as coherent within some people's biographies, such as in the case of illness diagnosed from birth or early in childhood. It has been argued that in these cases the individual does not experience a shift from one trajectory to another, but rather a continuity of biography (Williams 2003; Williams *et al.* 2009). Biographical disruption might also not be experienced by older people diagnosed with diseases which are

associated with their life stage. For example, Sanders *et al.* (2002) and Faircloth *et al.* (2004) found that their interviewees drew on age to construct a discourse of normality when talking about their experiences of osteoarthritis and stroke respectively. Faircloth *et al.* identified what they termed a ‘biographical flow’ in the narratives of their participants, who seemed to view illness as inevitable and part-and-parcel of old age.

Social circumstances also shape how people experience illness in relation to their biography. Bury (1982:169) wrote that the onset of “chronic illness involves a recognition of the worlds of pain and suffering, possibly even of death, which are normally only seen as distant possibilities or the plight of others”. However, this may not be relevant to those people who are already familiar with the worlds of pain and hardship (Pound *et al.* 1998). In their study of the experience of stroke in men and women aged between 40 and 87 (average age 71), Pound *et al.* found that the stroke often seemed unimportant to the participants in the context of poverty and other illnesses which characterised many of their lives. Similarly, in her study of the experiences of women who were HIV positive, Ciambrone (2001) found that women identified other events in their lives as being more disruptive than the HIV diagnosis, such as abusive relationships, drug and alcohol abuse, and separation from their children. These studies highlight the importance of contextualising illness within the social circumstances of the lives of individuals, and they sensitise researchers to avoid the assumption of universal biographical disruption (Williams 2003).

However, it should not be assumed that the experience of illness in difficult social circumstances does not produce biographical disruption, particularly when the illness threatens key aspects of identity. The lack of an engagement with gender in Bury’s work has been criticised (Ciambrone 2001; Wilson 2007). For example, Bury did not explore the implications of serious illness for the caregiving responsibilities of women, and how interference with these responsibilities impacted on women’s identities (Wilson 2007). Wilson (2007) explored biographical disruption in the context of HIV infection,

interviewing twelve women who were HIV positive and had children. Despite also having experienced difficulties such as abusive relationships and substance abuse, as in Ciambrone's (2001) research, these women still experienced HIV as biographically disruptive because of the way it threatened their identity as mothers, which was a central source of identity for the women. HIV was experienced as a fundamental threat to their motherhood both in terms of stigma, and the possibility of leaving their children without a mother. This suggests that the relationship between illness and biography is more complex than Bury first considered. For example, even in difficult circumstances, being young and diagnosed with breast cancer could mean biographical disruption, as while young women may already be familiar with hardship, they may feel that their gender identity as young women is challenged by breast cancer.

In this thesis, I will be drawing on the concept of biographical disruption in light of these more recent developments of the theory, mindful of the significance of social context and how it shapes the experience of illness as biographical disruption. In the rest of this chapter, I evaluate existing literature in terms of how well it has considered the significance of biographical disruption in exploring the impact of breast cancer on young women's identities.

Research about biographical disruption and the experience of cancer

Researchers have drawn on the theory of biographical disruption in several studies about cancer (Mathieson and Stam 1995; Rozmovits and Ziebland 2004; Leveahlahti *et al.* 2007; Cayless *et al.* 2009; Hubbard *et al.* 2010; Hubbard and Forbat 2012), and women's experiences of breast cancer (Sinding and Wiernikowski 2008; McCann *et al.* 2010; Trusson 2013; Liamputtong and Suwankhong 2015), but not in studies specifically exploring younger women's experiences of breast cancer. This presents a significant gap in knowledge, given the importance of age and life stage at diagnosis as highlighted earlier.

Making sense of cancer within a biography

Bury argued that people ask ‘why me?’ questions when they are diagnosed with illness, and that to address these questions involves looking back on their lives in order to make sense of the diagnosis in the context of their biography. In studies about the experience of cancer, it has been found that participants often reflect back on their previous health and lifestyle, in order to make sense of their illness and in their search for meaning (Levealahti *et al.* 2007; Cayless *et al.* 2009; Trusson 2013).

In Trusson’s (2013, UK) study about the experiences of 24 women aged 42-80 (average age 55) who had completed treatment for breast cancer or ductal carcinoma in situ (DCIS), participants searched for a cause of their breast cancer in their biography. Some women talked about external factors, such as significant stressful events in their lives (e.g. a wrongful arrest, being made redundant, and leaving an abusive relationship), and some blamed their behaviours, such as not breastfeeding. Some women in the study did not ask such questions, however, feeling that it was beyond their control, and still others turned to their religious or spiritual beliefs to explain their diagnosis. Liamputtong and Suwankhong (2015, TH) explored biographical disruption in twenty Thai women diagnosed with breast cancer, 5 of whom were below the age of 49. They too identified religion and spirituality as a significant resource which the women drew on when responding to their diagnosis. For example, some of the women felt that by conducting religious practises, such as meditating and taking food to Buddhist monks, they would live longer after their diagnosis.

In Bury’s (1982:170) work, he talked about the way that chronic illness ‘creeps up’ and that people may try to normalise their symptoms until they reach a point at which they decide to seek help. Diagnosis can therefore be experienced as a relief because it legitimates their symptoms. For many women, a breast cancer diagnosis will not be experienced in this way because their cancer is found through routine mammography rather than through symptoms.

This is, however, different for women diagnosed under the age of 47 as they do not attend routine screening in the UK unless their family history indicates the need. Burles (2010) found that two women with breast cancer in her study of young people with illnesses, had to push their GPs to refer them because of their age, and one of the women spoke about how the eventual diagnosis legitimised her symptoms, similar to Bury's findings. This indicates that age and life stage can shape how young women experience the onset of symptoms, and also how health professionals respond to them.

Earlier in the chapter it was illustrated that old age and a life characterised by hardship may mean that individuals are able to make sense of illness in their biography (e.g. Pound *et al.* 1998; Ciambrone 2001; Williams 2003). Research has explored this in the context of breast cancer to some extent. Liamputtong and Suwankhong (2015) found that some of the older women in their study described feeling that, because they had lived for a long time, they were more able to accept having breast cancer. However, the authors do not provide an in-depth analysis of the differences between the younger and older women in their study. Sinding and Wiernikowski (2008, CA) interviewed 15 women who had experienced breast or gynaecological cancer in their 70's and 80's, and found that some women viewed cancer as less disruptive in the context of other conditions such as visual impairment or diabetes, which had greater implications for the loss of independence. However, they also found that, for some, older age and hardship rendered chronic illness particularly disruptive. For example, one woman felt that, having struggled her whole life to take care of her children and make sure they had opportunities; she was entitled to an easier time in old age, and for her cancer was viewed as particularly unjust. This literature provides an insight into the perspectives of older women with cancer, and indicates the complex picture which emerges at the intersection of breast cancer, social inequality, and age. However, research can build upon this to further explore the significance of age at diagnosis.

Young women diagnosed with breast cancer are more likely than older women to have a BRCA genetic mutation or a family history of breast cancer (Brennan *et al.* 2005), and this may be significant in how they make sense of their diagnosis. Cayless *et al.* (2009) found that, for some men, a family history of prostate cancer was not protective against the shock of their own diagnosis, while others were able to draw on it to contextualise the diagnosis within their family experiences, which mitigated biographical disruption for these men. They also found that perceived genetic susceptibility may have lessened the shock of diagnosis, but not the realities of managing the prognosis and effects of treatment.

Gender identity

Existing research suggests that breast cancer can be experienced as a challenge to a woman's gender identity, as discussed in more depth in Chapter Four. Wilson (2007) argues that when an illness threatens a woman's identity as a mother it can be experienced as biographical disruption. Trusson (2013) found that, for the participants in her study, motherhood and family relationships were central to their experience, and being able to continue in their role as mothers throughout treatment mitigated the impact on their identity. None of the women in Trusson's study reported that breast cancer interfered with their plans for children, however, and this might be significant in young women's experiences of breast cancer. Research has found that young women feel that the impact of breast cancer on their fertility is a threat to their identity as women, discussed further in the next chapter (Dunn and Steginga 2000; Wilmoth 2001; Klaeson and Bertero 2008).

As well as the impact on fertility, there may be other ways in which breast cancer threatens a young woman's position as a mother. For example, breastfeeding is culturally associated with being a 'good' mother (Murphy 1999), but breast cancer treatment may interfere with a woman's ability to breastfeed (Gorman *et al.* 2009). Connell *et al.* (2006) also found that

younger women were worried about passing on a susceptibility to cancer to their child, or experiencing a recurrence and subsequently leaving their children without a mother.

The experience of being diagnosed with breast cancer during pregnancy may be experienced as biographically disruptive and disruptive of gender identity. One woman in Kirkman *et al.*'s (2014) study had terminated her pregnancy upon diagnosis in order to begin treatment. Kirkman *et al.* argued that the woman felt she needed to justify her decision in terms of wanting to remain alive for the children which she already had. For example, she said "I was doing what was right for our family...that was already in existence" (p.7). The decisions and emotions which arise from being diagnosed with breast cancer during pregnancy may, the evidence indicates, be experienced as a threat to a woman's gender identity and as biographical disruption.

The research in this section has demonstrated that biographical disruption characterises the experience of cancer for many people, but that there are ways in which the personal and social circumstances, such as life stage and the knowledge of a family history, shape this. Research has also indicated that there is a relationship between gender identity and breast cancer, and this shapes biographical disruption. There is a major gap in the evidence as there is very little research exploring biographical disruption in the accounts of young women living with a history of breast cancer. Therefore, there remains a question about the extent to which biographical disruption characterises the experiences and perceptions of young women living with a history of breast cancer, and the nature of this disruption.

Survivorship

I now turn to cancer survivorship, which some young women may draw on to make sense of the disruption involved in the experience of living with a history of breast cancer (Kaiser 2008). I first introduce the concept of cancer survivorship and discuss how it has been used by relevant organisations and institutions in the UK. I then discuss research about the

perceptions of the concept held by those to whom the label ‘cancer survivor’ might be applied, demonstrating that research has found that it is a positive resource for some, but that people have diverse and complex views on it in relation to how it applies to them (Kaiser 2008; Morris *et al.* 2011; Documet *et al.* 2012; Khan *et al.* 2012b; Trusson 2013; Stephenson *et al.* 2013). I will demonstrate that little research has considered the distinctive perceptions of young women living beyond breast cancer, and that there may be ways that age influences perceptions of survivorship.

The cancer survivor

The term ‘cancer survivor’ first entered discourse when Mullan (1985), a physician in the US diagnosed with cancer himself, suggested three seasons, or stages, of cancer survivorship. In his model, the first stage begins during diagnosis and treatment, followed by a stage characterised by remission or survival, and a final stage of permanent survival or cure. An intended result of Mullan’s definition was that those with a poorer prognosis were no longer separated from those with a good prognosis, as survivorship was now understood to begin from diagnosis and continue for the rest of a person’s life. The label ‘survivor’ has since been employed in both an academic and activist context (Lerner 2001; King 2006). It can be understood as a response to the challenges raised by a cancer diagnosis, and a resource to draw on when performing the work of reconstructing one’s identity after cancer (Kaiser 2008).

The National Cancer Survivorship Initiative (NCSI) was set up in the UK in 2008 and, following Mullan’s conceptualisation, defines ‘survivor’ as anyone “undergoing primary treatment, those who are in remission following treatment, those who are cured and those with active or advanced disease” (Department of Health 2010:21). To launch the NCSI, Macmillan Cancer Support and the Department of Health held a workshop with people affected by cancer, during which attendees were asked to vote for the term they felt best

described the period after diagnosis of cancer. 42% voted for ‘living with and beyond cancer’ and 36% voted for ‘survivorship’, with the remainder of votes split between ‘life after cancer’, ‘cancer rehabilitation’ or ‘none of the above’ (Wetherall *et al.* 2008).

Debate is ongoing about whether it is important to discuss how people with cancer are labelled (e.g. Ehrenreich 2008; Khan *et al.* 2012a; Bell and Ristovski-Slijepcevic 2013; Surbone *et al.* 2013). Bell and Ristovski-Slijepcevic (2013) have pointed out that applying a label to a large and heterogeneous population, some of whom find the term alienating, should be avoided if possible. Research about the meaning of the term for those to whom it is applied is limited, particularly in the UK, but suggests that some people find it to be at odds with the reality of their experience, and it may even present a barrier to seeking help for ongoing physical and emotional issues (Little *et al.* 2002; McKenzie and Crouch 2004; Kaiser 2008; Khan *et al.* 2012b; Pertl *et al.* 2014; Stephenson *et al.* 2013). I now review this research.

Research about the meaning of the term ‘cancer survivor’ to people with a history of cancer

Some research has found survivorship to be a positive resource to draw on when negotiating their identity after cancer. For example, Stephenson *et al.* (2013, CA) interviewed nine women who had been treated for breast cancer between the ages of 35 and 58 to explore their feelings about the term cancer survivor. Some women in their study felt positive about it, and the authors argued that for some it represented a sense of safety and “refuge from the immediate threats of death and cancer treatment” (p.70). Some of the women in Kaiser’s (2008, US) study, in which she interviewed 39 women aged 28-87 (mean age 52), felt it reflected the way that they had found the strength to ‘beat’ the disease (p.83). Kaiser also described one woman who felt she identified as a survivor before she was diagnosed with breast cancer because of previous difficulties throughout her life, which suggests that, for

her, cancer survivorship represented a biographical continuity or reinforcement of her identity. She described it as “one more notch on the survival bedpost” (p. 83).

Morris *et al.* (2011, AU) found that taking part in a group activity with other women who had had breast cancer promoted a positive shift in how some women perceived themselves as survivors. Although not all women in the study experienced this shift, Morris *et al.* suggested that experiencing membership of a group promoted a sense of security and belonging amongst the women, and enabled them to view ‘cancer survivor’ in a positive light. A study which used telephone interviews to explore the meaning of the term survivor amongst women who had had breast cancer, found that 107 of the 112 participants considered themselves to be cancer survivors (Documet *et al.* 2012, US). Kaiser (2008), however, found that 19 of the 39 women in her study did not refer to themselves as survivors. A major difference between these two studies is that Documet *et al.* recruited their participants from events held by organisations such as ‘Susan G. Komen for the Cure’ which were perhaps likely to foster the survivor identity, whereas Kaiser recruited through cancer support centres and personal referrals. Some researchers have emphasised that many of those who do identify positively with survivorship do so with certain caveats (Kaiser 2008; Khan *et al.* 2012b). For example, a woman in Kaiser’s study said “[survivorship] means I have won a huge battle in a war that will last the rest of my life” (2008:83).

The above studies were conducted in the US (Kaiser 2008; Documet *et al.* 2012), Canada (Stephenson *et al.* 2013), and Australia (Morris *et al.* 2011). The only studies in the UK on this topic were conducted by Trusson (2013) and Khan *et al.* (2012b). Trusson’s doctoral research was conducted with women (aged 42-80) living with a history of breast cancer. As part of her broader study about the experience of breast cancer, she found that some women perceived the survivor identity negatively because they felt it did not reflect their experiences, and it was felt that only those who had suffered most throughout their treatment deserved to be called brave or survivors. Khan *et al.* (2012b) explored the meaning of the

term with 40 people who had experienced cancer at various sites, including 15 women with a history of breast cancer. Their participants were aged 46-92 at interview (mean age 71), and were 5-22 years post-diagnosis, and had diverse responses. Some, like Trusson's interviewees, felt that they could not be considered cancer survivors because they did not feel they had 'earned' the label as they had not had to beat high odds or go through intensive treatment. Others, in contrast, viewed it as a straightforward statement of fact: they had been diagnosed with cancer and were still alive and had therefore survived. Many participants felt ambivalent about it, feeling that it was at odds with their worries about recurrence, or that it implied that survival was a choice, whereas in reality it was more to do with luck, or good medical care. Some people felt that they did not want to identify as a cancer survivor because they felt that cancer was not a major part of their identity, and they wanted to be known for other experiences and attributes. These two studies indicate that people in the UK with a history of cancer have diverse opinions on the term 'cancer survivor', but they do not provide insight into the experiences and perceptions of young women living with a history of breast cancer.

It has been argued that the discourse of cancer survivorship places too much emphasis on survival, rather than on quality of life after cancer (Little *et al.* 2002; McKenzie and Crouch 2004; Kaiser 2008). The survivor is cast as "someone made normal" by others (Little *et al.* 2002:176) and this leaves little space for expressing ongoing physical symptoms or fear of recurrence. In this way, it is not only a label, but a social role, which potentially obscures the suffering which people living after cancer treatment experience. Pertl *et al.* (2014) used a questionnaire to explore the experiences of cancer-related fatigue (CRF) in 73 participants (mean age 51), 21 of whom were women with a history of breast cancer. They found that there were two barriers to people expressing their symptoms of fatigue. Firstly, the participants perceived that cancer was considered to be higher on an illness hierarchy than CRF, and, therefore, because participants had survived cancer they felt that they should not complain about 'lesser' problems. Secondly, CRF was seen to be at odds with the survivor

identity, which should epitomise health, and so people with CRF felt unable to express their symptoms. The fact that CRF is a contested illness with no medically-defined cause added a barrier to being ‘legitimated’ by the medical profession (Bury 1991:57). Social perceptions held about cancer survivorship may cause people living beyond cancer to feel unable to seek help or share their ongoing physical side-effects of cancer and its treatment.

Differences in terms of perspectives of the label according to age have been indicated in some studies. For example, Kaiser (2008) found that survivorship was less salient amongst the women over 65 in her group, with these women drawing on a discourse of the ageing body instead to make sense of their experience, but Kaiser did not specifically describe the experiences and perceptions of the young women in her study. Helgeson (2011) used a quantitative questionnaire to determine the extent to which 240 US women (mean age 59) living with a history of breast cancer had integrated the cancer survivor identity into their lives, what she termed ‘survivor centrality’. She found that age was the only demographic variable which had a significant effect, as higher survivor centrality was associated with younger age. However, because of the quantitative nature of this study it was not possible to explore why this might be the case. Further, because Helgeson did not provide a detailed age range of her participants, it is unclear if there were any women under age 45 included in the study.

This research has demonstrated the diverse perceptions which people with a history of cancer hold about the term ‘cancer survivor’, and some has indicated that age, or life stage, at diagnosis, may inform the extent to which women adopt a survivor identity. However, there remain questions about the significance of age and of biographical disruption in understanding young women’s perspectives of survivorship. Many people reject the cancer survivor identity because it does not reflect their experiences. Moreover, it is viewed as harmful and restrictive by some, as it restricts a person’s ability to seek help for ongoing symptoms.

Liminality

I have argued above that research suggests that young women may experience biographical disruption as a result of cancer, and that while cancer survivorship might be a positive resource for young women to draw on after breast cancer, it may not adequately explain their experience. In this section I introduce the concept of liminality (Turner 1967), which may be able to account for the uncertainty experienced by those living with a history of cancer.

Liminality may be able to provide a more nuanced understanding of living with a history of cancer, wherein people find that they feel neither healthy nor ill.

The concept of liminality

Liminality as a concept first originated in anthropological studies of rites of passage (Gennep 1960; Turner 1967). Such rites of passage were observed to begin with a severing of the connection with a previous social position, followed by an ambiguous stage, before the individual re-enters society with a new identity and occupies a different position in the social structure (Hockey and James 2003; Blows *et al.* 2012). The ‘liminal’ state is the middle stage, characterised by uncertainty and in which the person is situated “betwixt and between fixed social positions” (Hockey and James 2003:24).

Although the concept emerged from anthropological studies, it has been used in recent decades to describe other phenomena, such as the experience of living with a history of cancer. Little *et al.* (1998) argued that a person who has had cancer enters into a state of liminality in which he or she is classified as neither ill nor well. Little *et al.*’s formulation differs from the earlier anthropological work because they do not conceptualise it as three separate stages, but as a process; “an enduring and variable state” (1998:1490). Little *et al.*’s formulation echoes Sontag (1990:3), who argued that people who have had cancer belong fully to neither the “kingdom of the well [or the] kingdom of the sick”, as well as Frank’s (1995) description of the ‘remission society’.

Whereas Bury's (1982) conceptualisation of biographical disruption provides an understanding of the adjustment to a chronic illness trajectory often characterised by 'growing dependency' (1982:169), liminality facilitates insight into those whose experiences blur the boundaries between ill and healthy. While women living with a history of breast cancer may not currently have cancer, their history of cancer engenders uncertainty about the future in terms of recurrence and health status. Liminality also provides an alternative to the survivorship concept. Whereas survivorship suggests a return to normality and to health, the reality of the experience of living beyond cancer treatment may contradict this. Liminality, therefore, offers a more nuanced understanding of the experience of living beyond cancer than biographical disruption or survivorship, as will be demonstrated in the review of existing research below.

Research about liminality and cancer

In Little *et al.*'s (1998) study about the experiences of people living beyond colorectal cancer, in which they first used liminality to describe this phenomenon, three themes emerged which they argued constitute a liminal state experienced by the interviewees. These themes were: 'cancer patientness'; 'communicative alienation'; and 'boundedness' (p.1486). Cancer patientness referred to the immediate impact of the cancer diagnosis, but also the persistent identification as a cancer patient by the interviewees regardless of length of time since treatment. Little *et al.* argued that the respondents continued to speak from the position of a cancer patient and described the ways that everyday life was irreversibly changed, and cancer occupied their thoughts most days. Communicative alienation involved the recognition that other people could never fully understand the experience unless they had been through it themselves. Interviewees talked about a sense of alienation and separation they felt from those who had not had cancer. The theme of boundedness referred to the experience of feeling restricted in terms of time and space (such as staying in hospital during recovery from surgery), and the surrendering of social and working roles, as well as the loss

of autonomy experienced in ceding control of their body to medical professionals. At later stages, participants felt a sense of uncertainty about the future and limitations in the freedom to move through space, particularly because of the physical constraints which having a stoma bag entailed in terms of requiring access to bathrooms.

Further to Little *et al.*, a small number of studies have used the concept of liminality to explore experiences of cancer. Two explored prostate cancer experience (Navon and Morag 2004; Cayless *et al.* 2009), one explored breast cancer (Trusson 2013), and one explored the experiences of people with various types of cancer (Hubbard and Forbat 2012). This body of research has found that liminality characterises the experience of living beyond cancer because of the extent to which those living beyond cancer fear the threat of recurrence. For example, Hubbard and Forbat (2012) invited forty people with a history of cancer in Scotland to write up to two pages about their experience of living with cancer. The authors offer no breakdown of the group in terms of gender, but 15 had had breast cancer, and 15 of the participants were diagnosed aged 50 or younger. They argued that participants wrote about cancer as a continuing threat regardless of the time since diagnosis or the presence of long-term physical effects of treatment. The authors also found that cancer was written about as an ongoing threat in terms of recurrence more amongst participants diagnosed under the age of 50, but they did not explore why this might be.

Researchers in this area have emphasised the end of treatment and the resumption of normal routines as a time when individuals experience profound uncertainty and may enter a liminal state (Navon and Morag 2004; Trusson 2013). One woman in Trusson's study spoke about others around her who had commented on how she had changed in a negative way since cancer. She spoke emotionally about how her old self was "still in there" but not ready to "come out" just yet (2013:169).

Navon and Morag (2004) argued that changes experienced by men in their study who were receiving hormone therapy for advanced prostate cancer were best understood as liminal. The men reported feeling that the treatment had positive effects such as the reducing of pain and the difficulty of urinating, but that this had come at the cost of dramatic changes to their sexual abilities and sense of themselves as male. The treatment left them feeling simultaneously 'better' and 'worse' because, while the symptoms of prostate cancer had been remedied, they experienced other losses in terms of libido and impotence. Their intimate relationships had also lost a great sense of closeness because of this, as also described in Little *et al.*'s (1998) analysis. The prolonged nature of their treatment, Navon and Morag argued, made the participants feel that their liminal state was a permanent one. Cayless *et al.* (2009) expanded on Navon and Morag's work by further exploring the experiences of men with prostate cancer using biographical disruption and liminality as a conceptual framework. They found that the language used by the men often suggested that they were caught between fear of recurrence and hope of change, illustrating liminality.

Cayless *et al.* (2009) and Navon and Morag's (2004) studies also illustrate the significance of gender relations on the sense of liminality experienced by those who have had cancer, particularly when treatment results in changes to hormone balances in the body. The men in their studies perceived their hormonal treatment to be a challenge to their gender identity, and the impairment of their sex life as a result of their catheters further added to this. They felt unable to classify themselves into culturally available categories as they no longer felt able to refer to themselves as healthy, sexually competent men, and questioned the sense of masculinity which they had previously taken for granted. Socio-cultural ideas about masculinity and femininity therefore reinforced their experience of a liminal identity.

Liminality and fertility

A further aspect of living with a history of breast cancer as a young woman which may be understood in terms of liminality is the impact of treatment on fertility and hormonal status. Previous research exploring liminality after breast cancer (Trusson 2013) has not considered the distinctive experience of younger women in relation to fertility, and how this might be understood in terms of liminality. Concerns related to fertility have been found to be high amongst young women living beyond breast cancer (e.g. Thewes *et al.* 2003; Avis *et al.* 2004; Gould *et al.* 2006), and there have been calls for more research about the subjective experience of fertility and infertility after cancer (Halliday and Boughton 2011; Perz *et al.* 2014).

Researchers in this area (e.g. Halliday and Boughton 2011; Perz *et al.* 2014) have identified that a significant element of the experience of living beyond cancer as a young woman is that of the uncertainty about fertility. A large study (Perz *et al.* 2014, AU) involved a mixed methods survey of 1965 women (average age 54.1 years), with 381 women answering the open-ended questions about the effect of treatment for breast cancer on their fertility. Perz *et al.*'s study indicated that the experience of infertility after breast cancer may be experienced as biographical disruption, with women writing for example "it makes me feel like a failure as a woman and as a wife" (p.517), but it also highlights the importance of the uncertainty about infertility. For example, one woman wrote: "I am hoping that I am only experiencing a temporary menopause" (p.518), and another wrote: "I assume treatments have made me infertile, but don't know for sure. That's difficult" (p.518).

Another Australian study, conducted by Halliday *et al.* (2014), involved interviews with twelve women (aged 25-39) who were at least one year post-diagnosis of haematological cancer, finding that women living with uncertainty about their fertility after treatment felt profoundly different to their peers. The authors argued that this can be understood as feeling

‘othered’, or being positioned as different from the norm. Halliday *et al.*’s findings echoed Little *et al.*’s (1998) description of liminality. For example, they felt disconnected from others, finding it difficult to cope with the uncertainty of whether they would be able to go through the same experiences of having children as their friends and family. This is also reminiscent of the concept of communicative alienation as developed by Little *et al.* which related to the impact of cancer on personal relationships because of the dissonance between their experiences and the experiences of those around them. Halliday *et al.* also argued that the women in their study experienced a heightened awareness of the constraints of time, and a loss of the taken-for-granted assumptions that they would be able to have children, and that they had plenty of time in which to do so. This was exacerbated by uncertainty such as about how long it would take to have children, and whether they would need IVF treatment. In Little *et al.*’s formulation, they described the participants’ sense of being constrained by time and space as a result of the effects of treatment. This recent study about young women living beyond haematological cancer indicates that the concept of liminality may therefore have potential in understanding this experience and young women’s perceptions of fertility after breast cancer.

The above research has indicated that the experience of infertility after breast cancer may be biographically disruptive, but it has also highlighted the importance of uncertainty related to fertility and menopause after treatment for cancer. This existing research indicates that liminality may be a useful concept in understanding the experiences and perceptions of young women living with uncertain fertility status after breast cancer.

Conclusion

The framework of illness as biographical disruption has been shown to be useful in understanding the experience of living beyond cancer, but it has not been used to explore the experiences of young women living with a history of breast cancer. A critical approach to biographical disruption sensitises the researcher to the complex relationship between identity

and illness, and the ways that particular biographical and social circumstances shape the extent to which illness is experienced as disruptive. Research has demonstrated that people diagnosed with cancer search for meaning in their diagnosis and attempt to make sense of it in the context of their biography. It has also hinted that young women with breast cancer may struggle to make sense of it if they hold the perception that breast cancer normally affects older women. The concept of the cancer survivorship was discussed in this chapter, and research exploring the perspectives of those to whom it might be applied was evaluated. Research in the UK and in relation to young women is limited, but the research on the topic has indicated the varied and ambivalent perceptions which individuals hold about the survivor identity. It has also shown that ‘cancer survivor’ is not merely a label but also a social role, with associated social expectations which may result in obscuring the suffering of those living beyond treatment. The concept of liminality, which refers to the sense of being neither ‘healthy’ nor ‘ill’, and the experience of uncertainty after cancer treatment renders the idea of the ‘cancer survivor’ problematic. Research about uncertainty related to fertility after cancer indicates that this is an important issue for young women living beyond cancer, and also that liminality may be a useful theoretical concept to understand this.

Throughout this chapter and the previous, I have mentioned the significance of gender for young women’s embodied and biographically situated experiences and perceptions of living with a history of breast cancer, and this element of the theoretical framework, in addition to intersectionality, is now discussed in depth in the following chapter.

Chapter Four – Gender and intersectionality and young women’s experiences and perceptions of breast cancer

Introduction

In this chapter, I review the extent to which existing literature has explored the ways that gender and other intersecting forms of social oppression shape young women’s experiences and perceptions of living with a history of breast cancer. I do so from a feminist position which understands gender to be a social construction, and gender relations as not natural, but produced and maintained by everyday interactions and social structure (Kasper 1994; Jackson and Scott 2002; Smith 2007; Oleson 2011). The lives of young women living with a history of breast cancer, I will argue, are shaped by gender relations, and the intersection of gender with other social divisions, such as ageism, racism, and heterosexism.

Intersectionality is closely linked with feminism as it was originally developed by black feminist scholars who critiqued the neglect within feminist theorising of the impact of race on women’s experiences (Crenshaw 1989; Phoenix 1990; McCall 2005; Shields 2008). This chapter examines what previous research has revealed about the influence of the intersection of social divisions on the experiences and perceptions of young women living with a history of breast cancer.

This chapter begins with a discussion of the approach to gender and intersectionality which is taken in this thesis, supported by a brief profile of the work of feminist researchers in the area of breast cancer. Following this I go on to evaluate the extent to which previous research has explored the role of gender in the experiences and perceptions of young women living with a history of breast cancer. Three areas were identified as significant for young

women through a review of the literature: the experience of the effects of treatment in a social context which constructs breasts as central to femininity; the influence of gender on young women's accounts of the impact on fertility and motherhood; and the significance of gender in the performance of emotion work by young women during and beyond breast cancer treatment. Finally, I consider the insights provided by existing research about black and minority ethnic women, sexual minority women, and disabled women with breast cancer, followed by a discussion of the influence of socio-economic circumstances. These final sections explore the influence of intersecting social oppressions of racism, heterosexism, disableism, and the impact of financial demands on young women's experiences and perceptions of living with a history of breast cancer.

Approach to gender and intersectionality

Gender

The approach to gender which I take in this thesis is one in which gender is understood to be a social construction, and gender relations as produced through interactions and social structures rather existing naturally – also known as an anti-essentialist view of gender (Jackson and Scott 2002; Moore 2010). Decades of scholarly writing and research by feminists have explicated the socially constructed nature of gender, and demonstrated the effects of gender relations on the lives of women (e.g. Hochschild 1979, 2003; Oakley 1980; Smith 1987, 2007; Butler 1990, 1997; Young 1990, 2005; Annandale and Hunt 2000). The approach in this thesis recognises that, while gender is socially constructed, gender relations have material consequences for women's lives, and socio-cultural ideals about femininity may be central to a woman's identity (Young 1990, 2005).

Health has been an important topic in feminist sociological work for several decades. The women's health movement began in the 1960's as a social movement, and feminist academic literature on health has been an important area of study since the early 1970's

(Annandale and Hunt 2000; Moore 2010). Feminists have worked in many areas of health, from critiques of the medicalisation of women's bodies (Calnan 1984), to gender inequalities in health and healthcare (Nettleton 2006; Moore 2008). Recently, feminists such as Moore (2010) have called for further interrogation of the gendered dimensions of the 'new paradigm of health', which emphasises health promotion and the prevention of illness.

The work of several feminists in the area of breast cancer informs this thesis (such as Lorde 1980; Kasper 1994; Langellier and Sullivan 1998; Wilkinson 2000; Ehrenreich 2001; Thomas-MacLean 2004, 2005; Fish 2010). Thomas-MacLean (2004, 2005) has called for greater consideration of gender in studies about breast cancer, saying it is important "to critically examine the implications of constructions of femininity and female sexuality for women with breast cancer" (2005:201). Langellier and Sullivan (1998) argued that sexist power structures have been reinforced by past research about breast cancer, particularly in the discipline of psycho-oncology, because research has been preoccupied with the effects of breast loss and its impact on appearance. Feminists researching the topic such as Kasper (1994) and Thomas-MacLean (2004, 2005) have agreed, and Thomas-MacLean wrote that this "illustrates that patriarchal appearance norms may not only influence a woman's decision about treatment and reconstruction, but also govern research itself" (2005:201). A feminist approach, therefore, is useful in exploring how the experiences of young women living with a history of breast cancer are mediated by gender inequalities.

Intersectionality

Intersectionality is a theoretical paradigm which was developed as a critique of mainstream race studies which had neglected the experiences of women, and of mainstream feminism, which had tended to treat women as a homogeneous population, overlooking the distinctive experiences of women of colour (Crenshaw 1989; hooks 1990; Collins 1992, 1998; Phoenix 2006, 2011; Yuval-Davies 2006). Intersectionality theorists thus do not treat social

categories such as ethnicity and gender as “mutually exclusive categories of experiences and analysis” (Crenshaw 1989:139), emphasising that multiple social oppressions intersect with gender to produce subjective experience. For example, women of colour experience a gendered form of racism. Patterns of oppression and privilege are understood not as additive, but as mutually constituting one another, producing complex identities in a given socio-historical context (McCall 2005; Christiensen and Jensen 2012). Individuals are therefore understood to be located at the intersection of multiple categories, such as gender, ethnicity, class, sexual identity. From this perspective, the “limitations of gender as a single analytical category” are highlighted (McCall 2005:1771). Drawing on intersectionality, therefore, means that gender can be retained as a primary concept for analysis, but an essentialist view of gender and women can be rejected.

McCall (2005) distinguished between three different approaches to social categories within intersectionality: anti-categorical; inter-categorical; and intra-categorical. Her typology is useful in understanding the nuances in different approaches within intersectionality, which she uses to refer to all “perspectives that completely reject the separability of analytical and identity categories” (2005:1771). The first approach – anti-categorical – is located within post-structuralist theory, and, as the name suggests, seeks to deconstruct social categories in order to break down social inequality. Although this work has been useful in explicating the ways that social divisions are socially constructed, and how they may be broken down, it does not provide insight into the reality of social life which is enacted in relation to these social divisions. The second approach, the inter-categorical approach, aims to study the differences and interrelations between social groups. This recognises that there are relationships between groups, and that these have complex and variable material consequences in the lives of individuals, despite being socially constructed. Studies taking an intra-categorical approach explore the differences and interrelations within categories. Such research often takes the experiences of one particular social group as a starting point in order to explore how multiple intersections shape their subjective experience. For example,

Crenshaw (1989) examined the differences between black women and white women in race and sex discrimination cases. As McCall noted, traditional categories are used initially in order to identify groups at particular intersections, but intra-categorical research reveals diversity within the group, and the ways that the “complex texture of day-to-day life” is not determined solely by broader social structures (2005:1782).

Work in the area of breast cancer has highlighted the significance of women’s particular social position for the experience of breast cancer, through exploring the experiences of black and minority ethnic women with breast cancer (e.g. Ashing-Giwa *et al.* 2004; Banning *et al.* 2010; Blows *et al.* 2009; Patel *et al.* 2014), and lesbian women with breast cancer (e.g. Boehmer *et al.* 2007; Fish 2010; Jabson *et al.* 2011; Rubin and Tanenbaum 2011). In this thesis, I draw on an intra-categorical approach in order to recognise that the category ‘young woman’ is diverse, and explore the ways that other oppressions, including ageism, racism, heterosexism, and disableism, intersect to shape the experiences and perceptions of young women living with a history of breast cancer.

Having established the relevance of an approach informed by feminist and intersectionality theories, I will now turn to explore how existing research has illuminated the impact of gender on the experiences and perceptions of young women living with a history of breast cancer, before reviewing the current landscape of existing research on the impact of the intersection of social oppressions.

Ageism

This thesis is exploring the accounts of young women, therefore, ageism, and the way that it intersects with other social divisions, is a crucial element of the theoretical context. The work of social gerontologists and critical childhood scholars has contributed to an understanding of age as a social construct (Macnicol 2006). This refers to the way that there

exist particular expectations and norms which are ascribed to certain ages and life stages in a given social context, and people experience discrimination based on their age, or perceived age (Ginn and Arber 1995; Neugarten *et al.* 1996). Ageing has therefore come to be understood as a social process (Hockey and James 2003), and the ways that people experience oppression as a result of their age has been explored. Ageism has traditionally been conceptualised as affecting older people (Johnson and Bytheway 1993), but alternative definitions have been developed, and it can be understood as “the application of assumed age-based group characteristics to an individual, regardless of that individual’s actual personal characteristics” (Macnicol 2006:6). Ageism, therefore, affects all individuals from birth onwards (Itzin 1986; Johnson and Bytheway 1993).

Age discrimination, particularly in terms of how it affects older people, in the domain of health has been well researched, and there is evidence that ageism in health and social care also affects younger people (Roberts 2000; Robinson 2003). For example, in the case of breast cancer screening, the age limits set by the NHS discriminate against both older and younger women (Roberts 2000). Alderman *et al.* (2008) in the US found that surgeons discussed reconstruction more often with younger women than with older women with breast cancer. There is also evidence of younger women who have been told by doctors that their breast cancer symptoms cannot be cancer. For example, a woman in Burles’ (2010) study described how her healthcare providers downplayed her concerns about breast cancer symptoms because of her young age, and it was only because she persisted in demanding further investigation that her breast cancer was diagnosed. As well as this evidence of discrimination in health care, existing research has suggested that young women perceive older women to be less affected by the impact of treatment on their appearance. For example, the women in Connell’s (2005) study (below age 40 at diagnosis) felt that younger women are more exposed and subjected to cultural and beauty norms and, therefore, experience the influence of these differently, perhaps more strongly, compared to older

women with breast cancer. There are ways, therefore, that ageist assumptions inform young women's perceptions of life after breast cancer.

I will, therefore, be exploring the significance of ageism in the young women's accounts, both in terms of experiences of age-based discrimination in the healthcare setting, and the social expectations which accompany their particular life stage.

Research about the role of gender and breast cancer

Breast loss as threat to femininity

Breast cancer affects a part of the body which has strong cultural connotations of femininity and womanhood in Western society (Yalom 1997). Young (2005:76) wrote that, within patriarchal culture, a woman's "breasts are the daily visible and tangible signifier of her womanliness". Langellier and Sullivan (1998:85) argued that "the public nature of breasts gives primacy to how they look and signal femininity in the eyes of others". The woman who has had breast cancer may therefore be "positioned outside 'normal' femininity" as a result of treatment (Gilbert *et al.* 2010:405).

Research has found that women of all ages may experience and perceive a loss of femininity due to breast loss (Langellier and Sullivan 1998; Bredin 1999; Piot-Ziegler *et al.* 2010; Fallbjork *et al.* 2012). For example, a woman in Bredin's (1999:1117) study said, with regards to her female friends, "I felt they are a woman and I am not". Piot-Ziegler *et al.* (2010) interviewed women before and after reconstruction, and found that the fear of no longer feeling like a woman after mastectomy was a motivation for choosing reconstruction. This has also been found in research involving younger women (e.g. Connell 2005; Coyne and Borbasi 2009).

Research about women of all ages has also found that women who have mastectomies without reconstruction do not feel comfortable without breast prostheses because of the stigma they perceive they would face (Langellier and Sullivan 1998; Connell 2005; Burles 2010). For example, one woman in Langellier and Sullivan's study talked of the "challenges to be present in public single-breasted as a woman" (1998:87). It appears then that gendered expectations of women's bodies and cultural significance of breasts as feminine have an effect on the decisions women with breast cancer make about how to manage their altered bodies after mastectomy. This reflects a tension within feminist work in this area. Although it might be viewed as empowering to reject these norms and be seen in public without prostheses or choose not to have reconstruction (Lorde 1980), this may in reality be very difficult for women who do not want to face such stigma in their everyday lives. It also arguably neglects an important dimension of the experience of breast loss: that of the physical loss involved and its impact on the sensation and physicality of women's bodies, as discussed in Chapter Two. Although some women in previous research have indicated their agreement with Lorde (1980), such as a woman in Langellier and Sullivan's study who viewed it as important to not hide her mastectomy in order for people to "understand that there are a lot of us [mastectomy patients] out here" (1998:87), many women talk about the problems of living with this visible threat to their femininity in their everyday lives.

Emotion work

Feminists in the area of breast cancer have written about the expectations of women with breast cancer to have a positive attitude, and to avoid expressing emotions such as anger and grief (e.g. Ehrenreich 2001; 2008). This echoes the concept of 'emotion work', developed by Hochschild (1983, 2003). Hochschild distinguished between 'emotional labour' and 'emotion work', defining emotional labour as the "management of feeling to create a publicly observable facial and bodily display...emotional labour is sold for a wage", whereas emotion work "refer[s] to these same acts done in a private context" (1983:7).

Emotion work is therefore the work which people perform on their own emotions and those of others, for the benefit of others. Hochschild argued that the ways that people perform emotion work in everyday life is reflective of, and structured by, gender relations and norms. For example, women are traditionally viewed as being caring and emotional, whereas men are prescribed a role which involves appearing tough and rational, and it has been found by many researchers that women perform more emotion work than men (Cline and Spender 1987; Olicker 1989; Duncombe and Marsden 1993; Erickson 2005; Elliott and Umberson 2008), and recent research has focused on emotion work in same-sex relationships (Umberson *et al.* 2015). The concept of emotion work has, however, been criticised. For instance, it has been argued that the focus of research on women's emotion work has neglected the emotion work which men perform in relationships, and that the idea of emotion work as being rewarding or of benefit to the person performing it is rarely considered (Duncombe and Marsden 1998). In this section I argue that, although research has hinted that young women perform emotion work during and after breast cancer treatment, the concept of emotion work has not been utilised to explore this in detail, and its possible gendered nature.

Two studies (Coyne and Borbasi 2007; Klaeson and Bertero 2008) identified 'having to be strong' in young women's accounts, but the authors of both studies analyse this in terms of feeling pressure to feel back to normal, rather than examining the gendered nature of the phenomenon. In Coyne and Borbasi's (2007, AU) study, young women felt that they had to outwardly display courage and positivity, but this left them without an outlet for their own emotions which they perceived to be considered negative, such as anger or grief. Klaeson and Bertero found that young women in their study felt responsible for the emotional well-being of their families and partners, and were required to move on after treatment, rather than feeling emotions of distress or self-pity. One young woman said "I wasn't allowed to be the person I was, I mean like, I was actually so frail at first" (2008:189).

A Swedish study (Bilhult and Segeston 2003, SW) interviewed ten women who had been diagnosed with breast cancer and who had young children. The authors interpreted the experience of being a mother to dependent children and having breast cancer as “using the strength of motherhood to balance conflicting forces” (p.127). According to the authors, “feelings of having to go on...made the mothers suppress negative thoughts such as giving up” (p.124). Their study was focused on the women’s experiences of feeling that they had to survive for their children, but the authors did not explore the impact of the suppression of negative feelings, and the implications which this may have had for their everyday lives. Using a gender analysis, the ‘strength of motherhood’ which Bilhult and Segeston argue their participants described, might be re-framed as emotion work and feeling responsible for holding the family together at the expense of women’s own emotional support.

Previous research, therefore, has suggested that young women may feel a sense of responsibility to maintain the emotional well-being of their families, and they may perform emotion work in order to achieve this, but the concept has not been used specifically to analyse the experience. All women with breast cancer may have concerns about how their diagnosis will affect their family and friends, but the configuration of younger women’s relationships may mean that distinctive features of their experiences of this may arise. For example, younger women are more likely to have young, dependent children, and to be living in new marriages or relationships (Gould *et al.* 2006). Although it may be associated with the pressure to seem back to normal and to move on from the end of treatment, there may also be a gendered dimension which has not been previously explored. Previous research has also not considered if this emotion work is ongoing in the years after treatment. By using the concept of emotion work, the significance of this gendered role in the everyday lives of young women living with a history of breast cancer can be explored.

Research on intersecting oppressions and breast cancer

This section will explore the extent to which previous research has explored the influence of intersecting oppressions on young women's experiences and perceptions of breast cancer.

Gender and age in issues related to fertility and motherhood

Fertility and motherhood are central issues which arise in much of the literature which explores young women's experiences of breast cancer. A recent systematic review found that quantitative studies have indicated that issues related to fertility are the most important issues which young women with breast cancer require information and support about (Peate *et al.* 2009).

The ability to have children is viewed in contemporary Western society as central to womanhood (Siegel *et al.* 1999; Williams 2002), and the loss of this ability, or potential loss, is experienced and perceived in gendered terms, and may have a profound effect on a woman's sense of her position as a woman in society. Research has suggested that the experience of treatment-induced menopause (TIM) itself may be experienced by some young women as a profound loss of feminine identity (e.g. Dunn and Steginga 2000; Wilmoth 2001; Klaeson and Bertero 2008; Coyne and Borbasi 2009). For example, a woman quoted in Wilmoth (2001:282) said of TIM: "first you lose your breast. Then you lose your womanhood". This response illustrates that the menstrual cycle may be viewed as central to being a woman, and that treatment-induced menopause is therefore experienced in gendered terms. Furthermore, young women experience treatment-induced menopause at a life stage not normally associated with menopause. This may contribute to a sense of biographical disruption, as explored in the previous chapter, but it also means that age and gender intersect to produce young women's experiences of treatment-induced menopause.

Some research in the US and Australia has explored how young women with a history of breast cancer felt about future pregnancies, and how gendered expectations of motherhood have shaped their perceptions. For example, Siegel *et al.* (1997, US) found that incentives for pregnancy included affirming their identity as women. Connell *et al.* (2006) found that women in their study felt it would make them feel more normal to have a child, but were worried that they would be viewed as ‘bad’ mothers because they might pass on a genetic susceptibility to cancer, or because of the risk of experiencing a recurrence and the effect this would have on their children to see their mothers with cancer, or to lose their mother to the disease. Gendered ideas about motherhood also shape young women’s experiences of breastfeeding after breast cancer. Breastfeeding is intertwined with social expectations of mothers and is “treated as not only compatible with, but also indicative of, maternal morality” (Murphy 1999:201). After breast cancer, women may have difficulties breastfeeding, such as an inability to lactate in the affected breast (Gorman *et al.* 2009). Connell *et al.* (2006) found that women had to balance their desire to breastfeed with their fears that, if they were to experience a recurrence while breastfeeding, finding the lump would be more difficult because of changes to their breast tissue.

The impact of breast cancer on young women’s experiences and perceptions of fertility and motherhood, and the way that these are experienced in gendered terms, has therefore been explored to a certain extent. Treatment-induced menopause may be experienced as a loss of womanhood, and regaining fertility and having a child is considered a way of regaining a sense of womanhood. Further, issues related to breastfeeding are experienced in the context of moral discourses about motherhood.

There are several ways that this existing research can be built upon. There is very little research in the UK about young women’s experiences regarding fertility after breast cancer. Lee *et al.* (2011) explored young women’s experiences of being offered (or not) fertility preservation treatments in the UK, but this focused on the medical context and the treatment,

rather than on women's everyday experiences and perceptions of fertility after breast cancer. Also, the accounts of women diagnosed during pregnancy are missing from existing research. How do women diagnosed when pregnant experience and perceive motherhood and their position as mothers, in relation to gendered discourses about motherhood? The everyday lives of young women diagnosed when they have very young children could also be further explored. Existing research has shown that issues related to fertility and motherhood are experienced in gendered terms by young women with a history of breast cancer, and this informs the exploration of the young women's accounts in this thesis.

Black and minority ethnic women

As highlighted in Chapter One, there are differences in incidence and survival rates of breast cancer in terms of ethnic identity in the UK, with black and minority ethnic (BME) women less likely to be diagnosed, but more likely to die from the disease (Karbani *et al.* 2011). There may also be ways that the particular position of BME women in society shapes their lives with a history of breast cancer. However, research in the UK has primarily involved white women, and literature about BME women's experiences is relatively sparse (Banning *et al.* 2010; Patel *et al.* 2014).

Patel *et al.* (2014, UK) conducted interviews with black and South Asian women living in the UK with a history of breast cancer. They found that the BME women shared similar concerns to those identified in previous research by white women, but that there were also ways in which their cultural background shaped their concerns. They found, in particular, that the women valued experiential support from women from a similar ethnic and cultural background to themselves, and identified a support gap. Participants also expressed dissatisfaction with the range of products available to manage their altered appearance, such as prostheses, wigs, and lymphedema sleeves. The women had problems finding prostheses and lymphedema sleeves which matched their skin colour, and they found that wigs

designed through the NHS were limited, with one woman saying “I feel that those wigs don’t suit black people. They’re more for the European type”. Religion was also very important to many of the participants, and was an ongoing source of support for a number of the women, which has also been found in studies about African American women’s experiences of breast cancer (e.g. Bourjolly 1998, US; Henderson *et al.* 2003, US). Four women in Patel *et al.*’s study were under 45 at diagnosis, but the authors do not explore the particular experiences of these younger women.

Patel *et al.* also found that South Asian women, in particular, felt it was not appropriate for them to speak openly about the disease because of the shame attached to it, and the cultural importance placed on women maintaining the family’s honour. Another UK study, conducted by Banning *et al.* (2010, UK), did differentiate one way in which age informed BME women’s experiences. Their study, which involved women aged 22-76, compared the experiences of Muslim Pakistani women with breast cancer living in the UK and in Lahore, Pakistan. The authors found that disclosing their illness to family members was a source of distress for all of the women because of the stigma attached, but that young women had additional anxieties related to revealing their diagnosis to new in-laws because of the implications for fertility.

A study in the US demonstrated the intersection of gender and ethnic identity. Rubin *et al.* (2013, US) explored the perceptions of mastectomy and breast reconstruction held by African-American women, arguing that previous researchers have viewed the lower uptake of reconstruction amongst this group as a disparity to be addressed. They found, instead, that African-American women often chose not to have breast reconstruction because of culturally-informed beliefs about the body, such as breasts being viewed as less important to black women than to white women. On the other hand, some of the women who did choose to have reconstruction said that they made their decision because of the difficulty in finding a prosthesis to match their skin colour, highlighting the importance of racist structures

restricting the decisions of black women after breast cancer. These findings illustrate the complex intersection of gender with racism, as well as with culturally-informed beliefs, in the experiences and perceptions of BME women with breast cancer.

The research reviewed above has not explored *young* BME women's experiences thoroughly, and the ways that age intersects with ethnicity and gender, and this study aims to build on this existing research by contributing the voices of young black and minority ethnic women.

Sexual minority women

The assumption that lesbian and bisexual women are at higher risk of breast cancer has been proposed by researchers who have argued that a higher prevalence of risk factors, such as women remaining childfree and higher levels of alcohol consumption, exists in sexual minority communities (e.g. Valanis *et al.* 2000; Cochran *et al.* 2001). This assumption also exists in UK parliamentary policy documents (All Party Parliamentary Group on Cancer 2009), but the evidence on which this has been based is limited and conflicted, as a recent systematic review has demonstrated (Meads and Moore 2008). Whether or not lesbian or bisexual women are at an increased risk of breast cancer, the particular social position of sexual minority women shapes their experiences and perceptions of living with a history of breast cancer, as the research below demonstrates.

Research has identified several areas which present barriers to adequate health care for sexual minority women (Matthews *et al.* 2002), such as discrimination in healthcare, and the ignorance of health providers to lesbian health issues. A study by Matthews *et al.* (2002, US) used focus groups to compare the experiences of heterosexual and lesbian women with breast cancer. The researchers found that there was a great deal of similarity between the two groups (although numbers of lesbian participants in their study were small) in terms of, for

example, satisfaction with treatment outcome, but there were some differences. There were barriers to accessing experiential support for the lesbian women, such as perceiving that they would experience discrimination in such groups, and also that there would be an emphasis on breasts as the object of male sexual desire and important to sexual identity. They also found that women who hid their sexual identity from health providers reported more difficulties because of the burden of secrecy.

Young (1990) suggested that lesbian women may feel more able to be in public after a mastectomy, but this is based on the assumption that sexual minority women are less affected by the male gaze, and also that the male gaze is the most important consideration to women with mastectomies. Boehmer *et al.* (2007, US) conducted interviews with sexual minority women aged 41-61 and their partners about decisions surrounding reconstructive surgery. They found that the women perceived these decisions to be rooted in and shaped by their lesbian or bisexual identity. Rubin and Tanenbaum (2011, US), in their study about the decisions of lesbian women about mastectomy and reconstruction, found that their participants *were* vulnerable to the objectification of women and its consequences, and this influenced their decisions about reconstruction. Jabson *et al.* (2011, US) explored lesbian and bisexual women's experiences with breast cancer in health settings. As Fish (2010, UK) has shown, although the majority of participants did not report being treated with any less courtesy or dignity than others, they did report being assumed to be heterosexual, which can impact on a woman's ability to communicate in a meaningful way with her health care providers.

Most evidence about sexual minority women's experiences of breast cancer has been conducted in the US. Fish (2010) conducted the first (and currently sole) qualitative study specifically exploring the experiences of lesbian and bisexual women with breast cancer in the UK. She pointed out that very few lesbians and bisexual women are likely to come out to their GPs or to other health practitioners, and that this has an important impact in how sexual

minority women experience illnesses such as breast cancer. Fish interviewed seventeen women (four of whom were aged 41-50, and one was under aged under 40), and her research has shown that there is a range of ways that sexual minority women feel disadvantaged during breast cancer treatment. Fish found that lesbian and bisexual women often felt uncomfortable in hospital settings as a result of the heterosexism which they encountered, or felt they were likely to encounter. Perceived attitudes towards their sexuality were a barrier to asking questions and discussing issues such as relationships and effects on sexuality. Many of the participants reported difficulty in finding information relevant to them as lesbian and bisexual women, and some also expressed feeling out of place or excluded at cancer support groups.

Being a lesbian or bisexual shapes women's experiences and perceptions of breast cancer, whether through perceptions about decisions related to reconstruction, or in their interactions with health professionals and the heterosexism encountered. The particular experiences of young sexual minority women require further exploration.

Disabled women

There is very little research about the lives of disabled women with breast cancer, and existing research has focused on quality of care rather than from disabled women's own perspectives. There is a small body of research which has explored disabled women's access to breast cancer screening (Liu and Clark 2008; Truesdale-Kennedy *et al.* 2011), the quality of care which they receive (McCarthy *et al.* 2006; Iezzoni *et al.* 2011), and survival rates for women with physical impairments or learning difficulties (McCarthy *et al.* 2006). However, the everyday experiences and perceptions of disabled women living with a history of breast cancer from their own perspectives remain under-explored.

Iezzoni *et al.* (2011, US) conducted interviews with twenty women who had pre-existing mobility impairments before their breast cancer diagnosis, half of whom were under fifty. The main focus of the research was on the medical and physical outcomes of the treatment, and the research highlighted that being disabled had particular implications for choices about treatment, as well as issues regarding diagnosis. For example, mammography machines were not being well adapted enough to be lowered for women who are unable to stand. However, this research also provided some insights into the perspectives of disabled women living with a history of breast cancer. For example, one woman decided against chemotherapy because of her concerns about how it would affect her ability to be mobile in her wheelchair and ride her bicycle. She said “I want to hang onto the last of my health. If [the breast cancer] comes back, then I will march myself into chemo.” (Iezzoni *et al.* 2011:49). This highlights the relationship between breast cancer treatment and physical impairments, and the subsequent impact on disabled women’s lives and on their decisions regarding treatment. It also indicates that particular perceptions about risk and everyday life after treatment may arise from the position of disabled women. The focus on mobility and treatment outcomes in the study, while providing important insights, means that it did not shed light on, for example, how gender or other oppressions might intersect to produce disabled women’s experiences and perceptions of living with a history of breast cancer.

This very small body of literature reveals that pre-existing impairments have significant implications for disabled women’s access to screenings, diagnosis, and on their treatment decisions and the outcome of treatment. However, there is no discussion of how other oppressions such as gender, ageism, and racism, intersect in disabled women’s lives with breast cancer. Nor is there consideration of how the social construction of disability shapes women’s experiences and perceptions of living with a history of breast cancer.

The financial demands of breast cancer

Breast cancer is more commonly diagnosed in women from affluent areas, but women from areas of higher material deprivation have a higher mortality rate (Bray *et al.* 2004; Lawrence *et al.* 2011). Research has also shown that, in the UK, there exists a socio-economic gradient in terms uptake of breast cancer screening, and stage of disease at diagnosis (Adams *et al.* 2004; Lawrence *et al.* 2011). Macmillan Cancer Support (2006, 2013) has released reports showing the significance of financial demands of cancer. The reports imply that younger women may be particularly affected by the financial impact of breast cancer. For example, where a cancer patient is younger than 55, seven in every ten households experience a loss in income (Macmillan 2006). Further, their 2013 report documenting the extra costs of being a cancer patient showed that those groups hit hardest by these costs were those with dependent children, and those working full- or part-time, because of the combined loss of income with the costs of supporting a young family. However, there is very little research from young women's own perspectives about how the financial demands of living with a history of breast cancer.

Young women may be offered fertility preservation treatments before undergoing breast cancer treatment, such as emergency IVF. However, not all women will be able access this for free. In the NHS, a woman must be aged between 30 and 40 at diagnosis to be eligible (Lee *et al.* 2011), which means that women diagnosed in their twenties or forties who are pre-menopausal at diagnosis are not able to access such treatment unless they can afford to pay for it privately. Further, Lee *et al.* (2011) argue that not all young women are treated equally in discussions with health practitioners about fertility. For example, women in their study reported that some health professionals assumed that they did not need to discuss fertility options with them if they already had one or more children. There are, therefore, ways that age and financial circumstances may intersect to have an influence on the lives of young women living with a history of breast cancer.

Conclusion

In this chapter, I have demonstrated the approach to gender which will be adopted in this thesis, which understands gender as a social construction, but as an important analytical concept when exploring young women's lives after breast cancer. This informed my review of existing literature, which identified that gender is significant in women's experiences of breast cancer and shapes their experience of the impact of treatment. While some existing research hints that young women perform emotion management in their everyday lives after breast cancer, an analysis of this informed by gender and the concept of emotion work has not been conducted and may provide a deeper insight into this issue. Gender intersects with age to inform young women's lives, such as in terms of the impact of treatment on fertility and the experience of motherhood. There is a small but growing body of work which has explored the impact of social divisions on the experience of breast cancer, but the voices of *young* BME, sexual minority, and disabled women are missing from this literature. Drawing on intersectionality enables an essentialist view of gender to be rejected, and the ways that interlocking social divisions inform the experiences and perceptions of young women living with breast cancer to be explored.

The preceding three chapters have provided a review of the existing literature about young women's experiences and perceptions of living with a history of breast cancer. In the chapter which follows, I describe and evaluate the methodology and research design of this study.

Chapter Five – Methodology and research design

Introduction

In this chapter, I describe and evaluate the methodology underpinning the research, and the methods employed in the study. I also discuss the ethical issues raised, and reflect on my position within the research. The previous chapters have provided the theoretical context for the study, reviewed existing literature on the topic of young women living with a history of breast cancer, and identified areas for further exploration. The review has also illustrated the insights which can be gained through an exploration of women's subjective meanings in relation to their experience of breast cancer. In order to answer the research questions developed from this literature review, therefore, a qualitative methodology informed by interpretivism, social constructionism, and feminism, was adopted. In this chapter, I will demonstrate that social constructionist grounded theory (Charmaz 2006) was identified as in line with the aim of the research questions. This approach enabled the exploration of the experiences and perceptions of young women living with a history of breast cancer from the perspectives of the young women themselves, and located in their broader social context. Chapter Four demonstrated the significance of gender in women's experiences of breast cancer, but argued that research has often taken an approach which neglects the heterogeneity of women with breast cancer, and the impact of intersecting social divisions such as age, racism, and heterosexism. Methodological and ethical principles from feminism and intersectionality therefore also informed the methodology, aiming to make women central to the research, and to remain critical of the ways that women's experiences with a history of breast cancer arise from their particular social position.

In this chapter I will consider the theoretical perspectives underpinning the methodology, and the synthesis of interpretivism, social constructionist grounded theory, and feminism and

intersectionality in this research. I then explore the methods used in access and recruitment, and how these enabled me to reach a group of women which facilitated an exploration of diverse and varied experiences. The rationale for the use of a stakeholder panel and semi-structured interviews in this research, informed by social constructionist grounded theory and feminism, is then discussed. I then consider ethical dilemmas which arose in the research, and how these were addressed. The methods of data analysis are then discussed, examining how the systematic yet flexible guidelines provided by social constructionist grounded theory allowed the findings to be arrived at. Finally, I evaluate the research, exploring the use of validity and reliability in qualitative research methods, critically reflecting on my position within the research, and finally examining the limitations of the study.

Research questions

Below are the research questions which were developed through the review of the literature. This chapter discusses the methods used to address these questions.

Main question:

- What are the experiences and perceptions of young women living with a history of breast cancer in the UK?

Underlying questions:

- What are the embodied experiences of young women living with a history of breast cancer, and how do they perceive these?
- To what extent does biographical disruption characterise the experiences and perceptions of the young women?
- How are the experiences and perceptions of the young women informed by gender? And are these informed by other intersecting oppressions, such as racism and heterosexism?

Theory of methodology

All research is underpinned by theoretical assumptions about how the world can be understood and studied (Denzin and Lincoln 2003). This section discusses the theoretical perspectives which informed this thesis, exploring how a methodology located within an interpretive paradigm and underpinned by social constructionist grounded theory and feminism and intersectionality, shaped the methods chosen.

Interpretivism

Interpretive research can be defined as “all of those approaches to research that prioritise the interpretation of the actions and meanings of agents, over measurement, explanation and prediction” (Williams 1998:7). The objective methods of the natural sciences, it is argued, are not appropriate for research about the social world because individuals interpret the world around them in ways which are shaped by their given social, historical, and experiential contexts (Charmaz 2006; Barbour 2014). In order to understand how an individual experiences a phenomenon, in this case being a young woman living with a history of breast cancer, interpretivists emphasise exploration from the perspective of the individual experiencing it. As a result, qualitative interpretive research is able to identify diverse and complex experiences of a phenomenon. Interpretivists also seek to understand how a person’s location within wider social structure shapes their experiences. In order to understand a person’s experience, interpretivists argue, researchers must understand the context in which it occurs (Bryman 2008).

Social constructionism

Social constructionism, or constructivism, is a theoretical position which “recognises the mutual creation of knowledge by the viewer and the viewed, and aims toward interpretive understanding of subjects’ meanings” (Charmaz 2005:510). Social constructionists assume

that there is no single, discoverable reality, and that individuals ascribe meanings to experiences which are shaped by social, structural, and experiential context (Berger and Luckmann 1967; Denzin and Lincoln 2003; Creswell 2007; Green and Thorogood 2014). Social constructionists therefore aim to understand phenomena, such as the experience of having breast cancer at a relatively young age, from the perspectives of those who have experienced it, privileging their subjective accounts and the meanings which they ascribe to them. From this theoretical position, the social world is understood to be accomplished through social processes which are socially, historically, and culturally specific. As a result, the meanings of breast cancer, are not inherent, but arise out of social interactions. Rather than using positivist methods to access the ‘truth’ about women’s experiences of, for example, their bodies after treatment for breast cancer, the particular ways that young women experience and perceive their bodies after breast cancer are best explored through interpretive qualitative methods. Drawing on social constructionism also requires that participants’ accounts be located within a social structure and context. This approach privileges individual understandings and meanings, but acknowledges that there are wider social and structural forces involved in shaping these. Therefore, the ways that young women experience and perceive their bodies after breast cancer is not only personal and subjective, but is also situated in a context characterised by, for example, particular gendered meanings about young women’s bodies (Young 1990; Kasper 1994; Thomas-MacLean 2005).

Social constructionist grounded theory

The aim of grounded theory methods is to produce understanding of a phenomenon which is grounded in empirical data, by starting with “the concepts and internal constructs” of the participants, rather than with grand theories or hypotheses (Dyson and Brown 2006:24). The method is emergent and inductive. This means that it involves being open to what is happening in the data and possible interpretations, and remaining flexible so that themes and

issues which emerge as significant can be further explored. Rather than imposing rigid concepts on the data, the grounded theorist takes an iterative approach, and prioritises the “concepts, categories and...the very words used by the participants” (*ibid*:23). Grounded theorists begin analysis during the data collection stage, and use a method of constant comparison to develop an interpretation of the data. They engage with the data and participants so that the interpretation resonates with the participants and makes sense to them. The methods of grounded theory are therefore useful for research focused on understanding the experiences and perceptions of individuals in a given social context, and are thus well suited to exploring how individuals interpret the world and “construct meaning out of intersubjective experience” (Suddaby 2006:634).

Grounded theory was developed initially by Glaser and Strauss (1967), in order to address the gap which they encountered between social theory and empirical research (Kenny and Fourie 2014). At the time, the development of grounded theory challenged contemporary views of qualitative research as unsystematic or anecdotal, offering “systematic, yet flexible, guidelines for collecting and analysing qualitative data” (Charmaz 2014:1).

Within the early conception of grounded theory, knowledge gained through research was positioned as ‘discovered’ by the researcher by Glaser and Strauss, and the researcher was seen as an objective and neutral observer of this reality (Charmaz 2000). Thus, whilst it has been praised for its emphasis on participants’ perspectives, and its usefulness in research focused on understanding the experiences and perceptions of individuals in a given social context, grounded theory – the “discovery of theory from data” (Glaser and Strauss 1967:2) – remained in a positivist paradigm, with its emphasis on scientific rigour and method. Theory generated through grounded theory was thought to better reflect the ‘reality’ of social life in this early formulation (Glaser and Strauss 1967; Strauss and Corbin 1998). Charmaz (1990, 1993, 2006, 2014), a student of both Glaser and Strauss in the early days of grounded theory (Kenny and Fourie 2014), rejected the assumption that theory can be

‘discovered’ from data. In the light of contemporary developing paradigms in sociology, she developed a version of grounded theory to fit better with an interpretive and social constructionist framework, recognising that “any analysis is contextually situated in time, place, culture, and situation” (Charmaz 2006:131). Taking a constructionist approach “means learning how, when, and to what extent the studied experience is embedded in larger, and often hidden positions, networks, situation, and relationships” (*ibid*:130). Both Glaser (1978, 1992) and Strauss’s (Strauss and Corbin 2008) later modifications of grounded theory have been criticised for remaining within an objectivist and positivist paradigm (Macdonald and Schreiber 2001; Bryant 2002). Charmaz’s social constructionist version of grounded theory was therefore identified as appropriate for this research.

Debates about the practice of grounded theory have reflected ontological and epistemological tensions evident in Glaser and Strauss’s work, and have centred on issues such as when to conduct the literature review, the best way to allow theory to emerge, and the status of the researcher (Glaser 1992; Bryant 2003; Charmaz 2000, 2006; Strauss and Corbin 2008). There is ongoing debate about the timing of the literature review in grounded theory (Hallberg 2010; Dunne 2011). Glaser and Strauss (1967) wanted to emphasise that researchers may end up testing hypotheses which were taken from abstract theorising, rather than building a fresh analysis from the findings of the research, and they therefore suggested that researchers enter the field with little knowledge of existing literature (Glaser and Strauss 1967). Glaser (1992) continued to defend the need to delay a literature review until after the fieldwork, but Strauss challenged this original tenet (Strauss and Corbin 2008). An early literature review was not only required for this thesis as part of the university’s doctoral process, but it has also been seen as crucial to perform a literature review in order to establish a rationale for the study, formulate pertinent research questions, and identify what the research might contribute to the area (Suddaby 2006; McGhee *et al.* 2007; Hallberg 2010; Dunne 2011). The literature review also informed the methodology and research design. It was through the literature review that the homogeneity of previous groups of

participants was identified, and thus intersectionality became an important plank of the methodology. Kasper (1994) also pointed out that to conduct interviews about the experience of breast cancer without knowledge of the medical context of breast cancer would be difficult.

Furthermore, it might be possible to enter the field without having completed a literature review, but it is not possible to ignore “cognitive reservoirs of previous experience and knowledge” (Bryant 2002:33), and the experience and position of the researcher would still influence the research and the theory developed. Recognising the position of the researcher in the study is crucial to a constructionist approach. In Glaser and Strauss’s conceptions of grounded theory, the researcher is viewed as an objective and neutral observer: an objectivist stance (Bryant 2003). Social constructionism emphasises the importance of recognising the subjectivity and position of the researcher, and the researcher’s active involvement in the construction of study findings, in line with a social constructionist understanding of the world (Charmaz 2006). This approach recognises that research is an engagement undertaken by individuals with their own backgrounds, knowledge, assumptions, and interests (Bryant 2002; Charmaz 2007).

Therefore, an approach can be taken by the grounded theory researcher which allows a literature review before entering the field, but remains critical of the way that pre-existing conceptualisations shape the research, and also preserves openness to different interpretations of the data. Grounded theory can be used to extend or develop existing theories, and a comprehensive reading of the literature around the topic is therefore essential (Suddaby 2006).

Bryant (2002) argued that the characteristics of grounded theorists, such as: sensitivity to the words and understandings of participants; a sense of absorption in the data; and ability to think critically during analysis, are characteristic of any qualitative researcher. But grounded

theory additionally requires consistently engaging with respondents and their accounts, and allowing flexibility to ensure that the resulting interpretation makes sense to the participants (Turner 1983; Bryant 2002). The research process viewed in this way is seen as a “process of engagement with actors-in-contexts; with the corollary that the researcher is also an actor-in-context(s)” (Bryant 2002:35).

The social constructionist grounded theory method as set out by Charmaz (2006, 2014) allows a more flexible and creative approach to the techniques of grounded theory than earlier conceptions, which allows for the emergence of the unanticipated, and Charmaz provides a “set of principles and practices [rather than] prescriptions or packages” (2006:9). The data analysis process involves two main phases: initial and focused coding. These are discussed in more detail later, but briefly, the aim of the initial phase is to become immersed in the data and remain open to potential ‘theoretical directions’ (Charmaz 2006:46) which the data could indicate. In focused coding, the most incisive and salient categories are identified and developed in order to sharpen the analysis. In constructionist grounded theory methods, the researcher constructs codes and categories which “crystallise participants’ experience” (Charmaz 2006:54) and therefore make sense in the empirical world.

Feminism and intersectionality

Key principles from feminism were also integral to the methodology of this research. This section discusses feminist principles regarding the status of situated knowledge and the position of the researcher, non-oppressive research, and a critical approach. These informed the methodology for this thesis, and are also consistent with a social constructionist version of grounded theory.

Feminist research aims to develop knowledge which is reflective of women’s own voices (Harding 1987; Oleson 2011; Hesse-Biber 2014), and positions women’s subjective

meanings as central to understanding their experiences. This is an epistemological position which values women's subjective experiences and the insights which these are able to reveal about the social world (Kasper 1994). Feminist scholars were at the forefront of developing an understanding of 'situated knowledges' (Haraway 1988), which understands knowledge as situated within a social context, shaped by experience, and subjective experience as arising from a particular social position. The practice of reflexivity was also developed by feminist researchers, which is a process of critical reflection on the way that the researcher's own experience, biography, and social position shapes the research (Smith 1987; Hesse-Biber and Piatelli 2012). A feminist epistemology is therefore consistent with a social constructionist approach to grounded theory, as it views research not as objective or value-free, and compels researchers to consider their own position within research.

Feminist principles emphasise a non-oppressive approach: carrying out research *for* women rather than *on* them, and prioritising the exploration of topics and questions which women themselves deem important (Oakley 1981; Harding 1987, 2008; Kasper 1994; Smith 2007). The study's findings are unlikely to directly benefit the interviewees, but several of the women stated to me that their reason for taking part was to help other young women who would be diagnosed with breast cancer. Making women's own perceptions central to the research also means that the findings should be useful and make sense to the participants (Harding 1987; Smith 2007; Oleson 2011).

Feminism also brings a critical lens to the methodology, viewing existing social and institutional relations as problematic and as produced and maintained through unequal social relations (Kasper 1994; Smith 2007; Oleson 2011). Thomas-MacLean (2005) has emphasised the ability of a feminist approach to allow researchers to explore what participants' experiences reveal about their social position. My research is also influenced by the work of Young (1990, 2005), who integrated an approach which privileged women's subjective and shared embodied experiences, such as of pregnancy and breastfeeding, but

also what their experiences reveal about the influence of social and institutional relations; the social context. Incorporating feminist epistemological and methodological approaches is thus consistent with the theoretical context of this study, aiming to shed light on the ways that gendered constraints influence young women's experiences and perceptions of living with a history of breast cancer.

Theories of intersectionality (Crenshaw 1989; Collins 1998; Phoenix 2006, 2011; Yuval-Davies 2006) also inform the methodology of this thesis. Crenshaw (1989) coined the term intersectionality to conceptualise theory and methodology which black and lesbian feminists had been carrying out (Phoenix 2013). This position emphasised the way that social divisions are interconnected with one another and produce particular experiences and oppressions. Black feminists' critiques of second-wave feminism were influential in highlighting that mainstream feminist theory often assumed women to be a homogeneous group, ignoring the distinctive experiences which result from being, for example, a woman of colour (e.g. hooks 1990; Collins 1992, 1998). Drawing on intersectionality, therefore, facilitates an exploration of how intersecting forms of oppression shaped young women's experiences and perceptions. There are ongoing debates within intersectionality which impact on the way that it informs research methodology. For example, while intersectionality researchers may view categories of identity and oppression as socially constructed, it is very difficult, if not impossible, to do research about them without reproducing them (Christiensen and Jensen 2012). Intersectionality theorists share the view that categories of oppression are not additive, but interrelated and mutually constructed (McCall 2005; Yuval-Davies 2006; Shields 2008). However, there remains debate about how many and which categories to use in a particular analysis. It has been suggested that these dilemmas can be solved pragmatically, according to the particular social, cultural, and historical context of the research (Christiensen and Jensen 2012; Phoenix 2013).

So far in this chapter I have profiled the methodology which informed the study. As demonstrated, the study is located with an interpretivist paradigm, drawing on three theoretical areas: social constructionism, social constructionist grounded theory, and feminist intersectionality. The advantages of drawing on these three areas include the privileging of women's own experiences and knowledges, acknowledging the social context of the experience under exploration, and understanding the researcher not as an objective observer, but reflecting on the subjective and active position of the researcher. The aim of such a methodological framework is to develop an understanding of the experience of breast cancer from the young women's own perspectives, and located within the given social context. The rest of this chapter sets out the design of the research, informed by the perspectives outlined above. Beginning with a discussion of access and recruitment, I then provide an outline of the study participants. I next discuss the stakeholder panel and the interviews, followed by a discussion of ethical considerations. A detailed discussion of the data analysis is provided, followed by an evaluation of the study and its limitations.

Access and recruitment of participants

Access to participants was negotiated through gatekeeper organisations. While the use of gatekeepers can be beneficial because they may be able to reach a greater number of relevant potential participants compared to the researcher working alone, there are also problems, such as having to concede control over who receives information about the study (Barbour 2014). However, the sensitive nature of the topic indicated it would be preferable to approach women through an organisation with which they had an established relationship (Creswell 2007).

Inclusion criteria

Non-probability, purposeful sampling was used in this research, an appropriate form of sampling for qualitative research, which aims for depth and richness of data, rather than representativeness (Fish 2006; Creswell 2007).

The inclusion criteria for the study were:

- Woman diagnosed with breast cancer at the age of 18-44
- Diagnosed at least twelve months previously and within the last ten years
- Completed initial treatment in the UK
- Not currently receiving treatment for cancer (including secondary or metastatic cancer), other than long-term preventative treatment such as Tamoxifen

The age range 18-44 was chosen for two reasons as a result of the literature review. Firstly, the majority (80%) of breast cancers are diagnosed in women over the age of 50, and 45 is well below this age, facilitating exploration of the experiences and perceptions of women diagnosed at an age with which breast cancer is not normally associated. Secondly, the literature review indicated that treatment-induced menopause is a significant issue in the lives of young women after breast cancer (e.g. Avis *et al.* 2004; Thewes *et al.* 2004; Archibald *et al.* 2006; Anderson *et al.* 2011). The average age of menopause is 50-51 (Hunter *et al.* 2011), and 45 is therefore well below this age, increasing the likelihood of reaching a group of women who were not yet menopausal at diagnosis. The time range of one year since diagnosis and within the last ten years was chosen because it was important that interviewees had had enough time to be able to think back on their experience of breast cancer, and to reflect on the impact of living beyond initial treatment (Rosman 2004).

The study included women who had completed initial treatment for breast cancer, and excluded those currently being treated for cancer or living with non-curable cancer. This is

because research has found that the experience of receiving palliative care has its own social and emotional issues and a substantially different illness trajectory (McLeod 1998; Rosenblatt 2006; Klimmek and Wenzel 2012). Initial treatment refers to treatment received with the aim of removing or destroying cancer cells present in the body, such as surgery to the breast, chemotherapy, and radiation therapy, usually in some combination. Many women will also receive long-term hormonal treatment after their initial treatment, with the aim of preventing breast cancer recurrence in the breast, and to prevent the growth of breast cancer cells which may have spread to other parts of the body (Davies *et al.* 2013). If their cancer was receptive to a particular protein, they will receive Herceptin for 1 year, and if it was oestrogen receptor-positive, they will receive Tamoxifen, usually for five years, although recently, experts have suggested it be recommended for ten years (Davies *et al.* 2013). Tamoxifen binds to oestrogen receptors, and therefore stops the growth of cancers which require oestrogen to grow. Women with hormone receptor-positive breast cancer may also receive monthly injections of Zoladex at the end of their initial treatment alongside Tamoxifen for two years as a preventative treatment (Breast Cancer Care 2012). Some young women may be given the hormonal treatment, Zoladex, during chemotherapy, in order to protect their ovaries from damage (Goodwin 2014). Although all women had finished their initial treatment, many of the women were still receiving long-term preventative treatment during the study.

One possible alternative study design could have been to include both older and younger women, and conducted a comparative analysis of their experiences and perceptions. There have been some studies which have used this method, such as Anderson *et al.* (2011) who held focus groups with 10 women aged over 40 at diagnosis, and 6 women aged 40 or under about their concerns about menopause after breast cancer, but I did not judge it to be appropriate for this study. To include older women would have reduced the number of young women that could be included, and, given that there exists a rich literature on which to draw in order to understand the experiences of older women, but research about younger

women is relatively sparse, it was deemed important to centralise young women's accounts as much as possible.

Negotiating access

I approached potential gatekeepers via email or telephone to ask for their assistance in recruiting participants, and, if they agreed, they were provided with information about the study to distribute (Appendix C). Multiple potential gatekeepers were identified, with the aim of reaching as diverse and wide-reaching a sample as possible. Throughout the recruitment phase, I approached multiple organisations which specifically provided health information or support to black and minority ethnic (BME) or lesbian, gay, and bisexual (LGB) communities, and this is discussed in more detail in the next section. First, I provide information about the gatekeepers from which participants were successfully recruited, illustrated in Table 1 below.

Table 1 - Recruitment

No. Participants	Gatekeeper/method
4	BCUK
2	Support groups
6	Coppafeel
5	BCC
2	Snowball
1	NBWN

I first approached Breast Cancer UK (BCUK), as I have links with this organisation through my volunteering work (assisting with setting up their social media sites), and they agreed to send out information about the study with their newsletter, and to allow me to advertise the study on their social media sites. BCUK is a small charity which focuses on lobbying the government and industry to tackle the environmental causes of breast cancer, specifically endocrine-disrupting chemicals in everyday products.

I next approached individual support groups and patient organisations which I sourced through internet searches and from the Macmillan Cancer Support website. Groups which specifically catered to younger women were approached primarily.

I then contacted Coppafeel, an organisation which aims to raise awareness of breast cancer amongst young women, focusing on self-examination. They agreed to send information about my study to women who had shown interest in volunteering for them, and also to place information about the study on their Twitter page.

Throughout the recruitment stage I had been in contact with Breast Cancer Care (BCC), a large nationwide charity which provides information and advice for those affected by breast cancer, including partners and family members of people with breast cancer. BCC has a thorough application process for researchers who seek BCC's assistance with their research, and required a completed application form and proof of ethical approval from the University of Warwick. This application was then reviewed by a panel of women living with a history of breast cancer – their Service User Research Partnership – and approval was given to allow BCC to help with the recruitment of participants. In exchange for this, BCC asked for four things: to be acknowledged in any subsequent publications and reports; that feedback is provided to all participants about the findings of the study; that a summary of the research is provided for dissemination to service users and carers; and that BCC are informed about any potential applications of the research findings. Information about the study was emailed to BCC's 'Breast Cancer Voices' – a group of women who take an active role in the charity. It was also placed on their forums, which are online spaces for those affected by breast cancer to communicate with one another.

Finally, one woman responded to information shared by the National Black Women's Network (NBWN) on Twitter, and two women were recruited through snowball methods, which involved asking participants to pass on information about the study to others (Barbour

2014). Snowballing methods have been particularly useful when trying to reach participants from marginalised or hard-to-reach groups (Fish 2006; Barbour 2014). Given that I wished to reach young BME and lesbian women, snowball sampling was identified as appropriate.

Reaching minority groups

Through the review of the literature, I identified that the influence of intersecting oppressions on the experiences and perceptions of young women living with a history of breast cancer was under-explored. As previously discussed, there is ongoing debate within intersectionality about the categories which should be used, but that this methodological dilemma can be solved pragmatically (Christiensen and Jensen 2012; Phoenix 2013). I made the decision to specifically explore the intersection of racism and heterosexism in young women's accounts, and to therefore purposively recruit BME and lesbian women to make up at least 25% of the sample. This was my starting point, but it subsequently emerged that there were two women in the sample who had identified as disabled before their cancer diagnosis, and it was therefore deemed important to explore the intersection of disability in addition to racism and heterosexism.

From the start of recruitment, I approached multiple organisations which specifically provided health information or support to BME or LGB communities, such as Muslim Women's Network; Asian Women's Cancer Group; Asian Women's Support Group; Somerset Lesbian Network; and Cancer Equality. Many of my attempts at contact went unanswered, although a couple of groups responded and said they would pass on information, or that they did not have any members who fit the age criteria.

As recruitment progressed and I began conducting interviews, it became clear that I needed to adopt further specific measures to ensure I was able to reach BME and lesbian women, otherwise I risked not including any. I therefore made the decision to ask women who

requested information about the study to provide some details of their background before making arrangements for an interview. I sensitively made it clear that I was, in the interest of being inclusive, hoping to speak with BME and sexual minority women, and asked them to indicate if they identified as belonging to these groups. I also mentioned to all participants after each interview that I was trying to reach women from these groups, and encouraged them to pass on my details to any women who fit these criteria. By asking women about their background at the first contact, I was able to construct a sample which included 3 BME women and 2 lesbian women. It should also be noted that I did not explicitly ask women to self-identify in terms of their sexual identity, and that there may, therefore, have been women who did not identify as heterosexual in the sample but who did not disclose this with me. This is reflected in Table 3 on page 108, wherein sexual identity is labelled ‘not known’ for all of those women who did not volunteer this information.

Breast Cancer Care’s mailing list and forums proved to be the most useful for reaching women who identified as BME or sexual minority. Being able to place information on a forum which was specifically aimed at BME women, and specifying in the information that I wanted to contact black and minority ethnic women seemed to encourage BME women to contact me, or so I gathered from meeting with them and listening to what they said before, during, and after the interviews. Such a straightforward method was easily utilised after some back and forth with BCC, but seemed to make a difference to those receiving it, making them feel that their voices were welcomed in the research.

Recruitment, exclusion, and withdrawal

In total, 48 women expressed an interest in participating. One woman took part in a pilot interview, three participated in the stakeholder panel, and twenty were interviewed. One woman withdrew before her interview because of another diagnosis of cancer in her close

family. For a variety of other reasons, provided in Table 2 below, 24 women who expressed an interest were excluded or withdrew from the study.

Table 2 – Exclusion and withdrawal

Number	Outcome
2	Did not respond after receiving information sheet
5	Did not respond to suggested interview dates
1	Withdrew
1	Aged >44 at diagnosis
1	Diagnosed within last twelve months
0	Diagnosed over ten years ago
1	Currently receiving treatment for secondary or metastatic cancer
2	Received treatment outside of UK
11	Reached target sample number
24	Total excluded or withdrew

Women who received information about the study via a gatekeeper organisation and were interested in taking part contacted me directly, usually by email. I sent them an information sheet and encouraged them to ask any questions they had. If, after reading the information sheet and asking questions, they were still interested in participating in the study and they met the inclusion criteria, I emailed them a number of suggested dates for an interview. The day before each interview I contacted each participant by telephone or email to make sure they were still available and happy for me to visit. The women who took part in this study were located across England and Wales (one woman had been treated in Scotland but now lived in Wales). The interviewing period lasted nine months, during which I travelled extensively across the country visiting large cities such as Manchester and London, as well as smaller towns and villages.

I now provide the demographic details of the participants.

The participants

Table 3 below provides the demographic information of the twenty interviewees. The ages of the participants at diagnosis ranged from 22 to 43, with the mean age at diagnosis 33.8

years, and the mean age at interview 37 years. The range of time since diagnosis was fifteen months to nine years, with the mean time since diagnosis being 3.5 years.

Most of the women (16) were married or cohabiting, one was civil partnered, two were in a relationship, and one was single. Most of the women who were not single had remained with the same partner or husband since their diagnosis, but Philippa and Faith had separated and met new partners. Melanie had been in an on-off relationship when she was first diagnosed, but had broken up soon after and had remained single since.

I interviewed three women who were pregnant when they were diagnosed, all with their first and, at the time of the interview, only, child. Six of the women had had children before they were diagnosed, of varying ages, and eleven had none. Of these eleven women, six were hoping to be able to have children in the future, and one – Kim – had adopted two children since her treatment. Olivia, Ruth, and Vanisha had never intended to have children, and Joanna was pregnant with her first child at the time of the interview.

Some potentially revealing occupational information has been removed from Table 3, but a suitable equivalent has been used. The women were from varying socio-economic backgrounds. All but three of the women were in paid employment at the time of the interview. One woman could not work due to being disabled, and another had been made redundant soon after her initial breast cancer treatment and was unemployed at the time of the interview. Another was a full-time mother. Five women were in part-time employment, either because of childcare, or as a result of the impact of treatment. One was a postgraduate student when she was diagnosed. Three of the women had private healthcare when they were diagnosed. Although the Townsend Deprivation Index (Townsend *et al.* 1988) is a rather blunt instrument as a result of the variation within postcodes, and the neglect of other factors which contribute to an individual's socioeconomic circumstances, it can help to give an indication of socio-economic circumstances. A higher score indicates higher levels of

material deprivation, and scores are allocated into five quintiles, with five having the highest deprivation score. Using their postcodes (where given) I found that eight women were from areas of high deprivation - in quintiles 4-5 – and nine were from less deprived areas in quintiles 1-3.

Table 3 – Participants (*explained further on pp.96-7)

Pseudonym	Age at diagnosis	Age at interview	Time since diagnosis	Relationship	Children	Occupation*	Townsend Quintile	Ethnic identity	Sexual identity	Pre-existing disabilities
Ailsa	41	43	1-2 years	Cohabiting	2 pre-diagnosis	Full-time mother	2	White British	Not known	No
Beverley	36	37	1-2 years	Married	2 pre-diagnosis	Office administration	5	White British	Not known	No
Catherine	38	39	1-2 years	Married	Pregnant at diagnosis	Marketing	1	White British	Not known	No
Charlotte	43	45	2 years	Married	1 pre-diagnosis	Local government	1	White British	Not known	Yes
Dawn	27	31	3-4 years	Married	Pregnant at diagnosis	Office administration	1	White British	Not known	No
Evelyn	33	34	1-2 years	Cohabiting	None	Production manager	Unknown	White British	Not known	No
Faith	22	28	6-7 years	In relationship	None	Local government	1	White British	Not known	No
Gemma	33	35	2-4 years	Married	None	Office administration	5	White British	Not known	No
Hayley	29	31	1-2 years	Married	1 pre-diagnosis	Local government	4	White British	Not known	No
Joanna	30	34	3-4 years	Married	Pregnant at interview	Physiotherapist	4	White British	Not known	No
Kim	29	33	4-5 years	Married	2 adopted	Teacher	3	White British	Not known	No
Lyndsey	31	32	1-2 years	Married	Pregnant at diagnosis	Office administration	1	White British	Not known	No
Melanie	27	32	5-6 years	Single	None	Therapist	4	White British	Not known	No
Naomi	26	30	3-4 years	Cohabiting	None	Account manager	Unknown	White British	Not known	No
Olivia	32	36	4 years	Married	None	Marketing	Unknown	White British	Not known	No
Philippa	36	39	3-4 years	Cohabiting	1 pre-diagnosis	Local government	2	White British	Not known	No
Ruth	43	52	8-9 years	Civil partnered	None	Unemployed	5	White British	Lesbian	Yes
Sarah	41	44	2-3 years	Married	3 pre-diagnosis	Personal Assistant	3	African British	Not known	No
Tabitha	36	38	2 years	Married	None	Unemployed	4	African British	Not known	No
Vanisha	43	47	4-5 years	In relationship	None	Teacher	4	Indian	Lesbian	No

The treatment information about each participant is provided in Appendix G. All women had completed their initial treatment, receiving a range of the most common forms of breast cancer treatment: surgery, chemotherapy, and radiotherapy. All women were interviewed after their first diagnosis of breast cancer, with the exception of one woman, Melanie, who had been treated twice after it was discovered to have spread to her neck one year after her first diagnosis. A number of the women received long-term preventative treatment such as Tamoxifen, Zoladex, or Herceptin. Fifteen women received chemotherapy, and seventeen underwent radiotherapy (two more women did not mention radiotherapy but may have received it).

Eight women were treated with a lumpectomy (tissue removed from the breast), and twelve women were treated with mastectomies (removal of the entire breast). Six women of the twelve who had mastectomies had reconstruction after initial treatments. At the point of interview, four women – Beverley, Gemma, Ruth, and Sarah – had not yet had reconstruction, either because of medical reasons or because they had chosen not to, but two (Beverley and Sarah) were planning on eventually. Dawn and Faith both had later reconstruction after preventative mastectomies. Vanisha, initially treated with a lumpectomy, subsequently had double preventative mastectomies with reconstruction, and Charlotte was soon to undergo the same. The young women's surgical history was often complicated. For example, originally Dawn had a lumpectomy, but, because of complications, she then had a mastectomy with no reconstruction shortly after her chemotherapy. Several months later, Dawn elected to have her unaffected breast removed because of her BRCA mutation, and then had double reconstruction.

Two of the women – Vanisha and Kim – had also elected to have preventative oophorectomies (removal of the ovaries), and Charlotte had had a full hysterectomy.

Stakeholder panel

The involvement of stakeholders in health research is well established in the area of service evaluation and development (Boote *et al.* 2002), and can be viewed as a form of ‘member checking’ (Creswell 2007:208), which is when the researcher engages with participants and asks for their views on the research (Green and Thorogood 2014). They have also been used in breast cancer research. For example, Fish (2010) used a stakeholder steering group to involve women in her study about lesbian and bisexual women’s experiences of breast cancer. Incorporating a level of young women’s involvement had both a theoretical and ethical rationale. From a theoretical perspective, the experiential knowledge of stakeholders may complement or challenge the researcher’s, and produce a more rounded, holistic view of the experience which resonates with them (Boote *et al.* 2002). The use of a stakeholder panel also contributed to the iterative nature of the research, consistent with a grounded theory approach, since the aim of grounded theory is to construct an understanding of the phenomenon recognisable to those people who are actually experiencing it (Charmaz 2006). Stakeholder involvement also reflects feminist methodological principles, as it makes the research more democratic (to a certain extent), and attempts to redress the power imbalance inherent in the researcher-participant relationship (Oakley 1981; Phoenix 1994; Harding 1987, 2008; Smith 2007). This can only ever be achieved to a certain extent, however, as Cotterill (1992:604) explains: “the final shift of power...is balanced in favour of the researcher, for it is she who eventually walks away”. Here, I discuss the composition of the panel, followed by a description of the meetings themselves.

Composition of the panel

The panel consisted of three women – Layla, Julie, and Hannah (pseudonyms) – who fit the study inclusion criteria. They were recruited after I contacted support groups in one city and asked women who responded from those groups if they would be interested in contributing to the development of the research, and were able to commit to three meetings over eighteen

months. I did not conduct individual interviews with the panel members. The roles of participants who take part in both a stakeholder panel and individual interviews may become blurred, and interviews might be shaped in some part by their knowledge of the discussions in the panel meetings (Boote *et al.* 2002). A question which arises through the use of a stakeholder panel is that of representativeness (Creswell 2007). Representativeness in this context does not refer to how statistically representative the sample is, but it invokes the need for a critical reflection on whose voices the members of the stakeholder panel are able to represent. In the case of this research, the women on the panel were relatively homogeneous in terms of background. They were all aged between 40 and 45 at the time of the panel, and had all completed their families before being diagnosed with breast cancer. All three were married, white, and able-bodied, and one woman had private healthcare. With this in mind during our discussions, I encouraged the panel members to also think about friends they had with breast cancer who were from different backgrounds or life stages, or to try to imagine being from a less privileged background or in a different familial situation, but this was inevitably limited.

Panel meetings

The first meeting was held prior to any interviews, and involved a discussion of the topics which were likely to arise during the interviews, and the ways that questions should be phrased and issues approached. At this initial meeting, we also spent some time at the beginning getting to know one another, and listened to short accounts of the experience of breast cancer from each woman. Two of the women already knew one another from a support group. The discussion which arose during this meeting contributed to shaping the interview schedule, helping to prepare me for topics which were likely to arise in the interviews, such as the importance of premature menopause, and the length of time of treatment. This first meeting also provided me with my first encounter of the cumulative impact of having breast cancer under the age of 45, which alerted me to the profound and

distinctive effects of breast cancer on young women's lives. It also sensitised me to the significance of the length of time which initial treatment takes. Going into the interviews following this, I felt better prepared for the variety of issues which would arise, and the ways that these *combined* to shape young women's lives after treatment.

The second meeting was held after 16 interviews had been conducted, and I shared a small number of the emerging findings in order to listen to their thoughts and opinions on these, and to consider new insights. I asked the women to consider if the findings made sense to them and fitted with their experiences and perceptions, and if there was anything significant which they felt was missing or inconsistent in the findings. The panel thus contributed to the iterative approach to the research. For example, this meeting alerted me to the fact that the impact on work and career had not been a particularly dominant topic in the interviews or findings, something which surprised the advisory panel, and which encouraged me to investigate this further in subsequent analysis and interviews. I was also able to explore issues which had surprised me in the interviews, such as how few women had positive views of the term breast cancer survivor, and the subsequent discussion informed my later analysis. At this meeting we also discussed 'emotion work' (Hochschild 2003), and how, or if, it was shaped by gender. At this point I was unsure if the participants would agree that there was a significant gender dimension to their experiences of emotion work, but the panel all agreed that there was in their experience.

The final meeting was held after all interviews had been completed, and while the findings chapters were being written. At this meeting, I shared two findings from each of the three findings chapters, and again asked the women to discuss their interpretations of them, and if they felt there was anything missing or which they disagreed with in my interpretation. In the discussion, the differences amongst women aged 18-44 emerged as an important point, and the life stage of a woman when she is diagnosed was deemed significant in the effect it would have on her life, and the support she would require. We also discussed the diversity

amongst women even of a similar age and life stage. The panel itself was a good example of this, since experiences and perceptions differed on many topics, even though the group were close in age and fairly similar in background.

Data collection

Qualitative, semi-structured interviews were selected as the data collection tool for this research. Other methods were considered. For example, narrative interviews were considered, which would have been consistent with a feminist approach as they would allow women to give their accounts precisely as they chose, with minimal contribution from the interviewee (Mishler 1986; Corbin and Morse 2003). Narrative methods have previously been used in this topic area (e.g. Shapiro *et al.* 1997). However, the flexibility which semi-structured interviews afford, and the ability to explore emergent themes and to use prompts to delve deeper into the young women's experiences and perceptions (Thomas-MacLean 2004), were seen as crucial to the research approach, allowing deeper exploration of the unexpected and unanticipated, a key aspect of grounded theory (Charmaz 2006).

Non-participant observation could also have been utilised in settings such as breast cancer charity events, or support groups meetings. For example, Bell (2009) observed support group meetings and examined the language used, in order to explore how cancer was socially constructed. However, the aim of this study was an in-depth exploration of the young women's own perspectives on living with a history of breast cancer, and, while such methods have been used in previous research to produce valuable insights into the language used by participants, and the ways that cancer is talked about, these methods would not necessarily have facilitated access to such rich data about their experiences and perceptions.

The interview has been an important tool for feminist researchers, viewed as a method which enables the voices of those otherwise marginalised to be heard (Aldred and Gillies 2008).

However, there are critiques of the use of interviewing in social research. For example, it has

become widely accepted that the data which results from an interview is not straightforwardly an authentic reflection of a reality, but it is an account of a particular form of interaction which is embedded within a socio-historical context (Atkinson and Silverman 1997; Sandelowski 2002; Alldred and Gillies 2008). It has also been argued that the interview situation compels participants to perform in certain ways, and to present a particular version of their stories (Atkinson and Silverman 1997). It cannot be assumed, therefore, that interviews offer direct access to authentic experience, but rather the result of an interview should be understood as a construction of an experience which emerges from the interaction between the researcher and interviewee. However, interviews are the most effective way of answering certain research questions (Charmaz 2014). The aim of this research is to explore young women's experiences and perceptions of living with a history of breast cancer and, therefore, the best way to do so was to utilise a method which facilitated the young women's reflection upon these. A compelling argument of the fit between semi-structured interviewing to social constructionist grounded theory is provided by Charmaz, who argued that "interviewing focuses the topic while providing the interactive space and time to enable the research participant's views and insights to emerge" (2014:85).

Having established the rationale for the choice of data collection method, I now describe the process of interviewing. Following this is a discussion of the ethical issues, which provides further details about the interviews.

Before the interview

Interviews lasted between 55 and 100 minutes, and all but three were carried out at the homes of the participants. The location of the interview was the choice of the interviewee. One chose her workplace and two chose to meet in public locations because this was more convenient for them. When we first met I aimed to put the interviewee at ease with some general conversation before beginning the interview, and also explained the purpose of the

research and my background. The participants were then asked to read and if they wished to take part and agreed to being audio-recorded, to sign the consent form (Appendix D). After this, some basic demographic questions were asked and completed (Appendix E). Once it seemed that we were both comfortable and ready, I switched on the voice recorder and began the interview.

The interviews

An interview schedule (Appendix F) with eleven questions or topics to address was prepared, but while I aimed to cover these, women were encouraged to tell their accounts in the order of their own choosing, and I tried to guide as little as possible. I always began with the open-ended question: “would you like to begin when you first thought something was wrong?” This usually then led women to describe their experience of discovering symptoms, going to their GP, and their diagnosis and treatment. The extent to which I asked questions or prompted women depended on how comfortable and confident each interviewee was in talking about herself for such a long time. Some women seemed more nervous or unsure and looked to me for guidance about what they should talk about, whereas others were able to continue talking with very little prompting from myself. Most of the interviews had a similar pattern of beginning with a long account from the discovery of symptoms through to the end of initial treatment. I would then ask interviewees to talk about their lives since the end of initial treatment since this was crucial to the focus of the research, and specific topics on the schedule which had not been discussed or which had only been mentioned in passing. Some of the questions and prompts were relatively broad and used more as a prompt to encourage women to continue their stories, such as: “can you talk about what life has been like since the end of treatment?” Others were more specific such as: “do you use the term breast cancer survivor about yourself?” It was always emphasised that women did not have to speak about topics which were particularly sensitive or upsetting, and I remained flexible, enabling

women to speak freely for long periods of time, so that the decisions about what was spoken about and when, were shared between us.

Ending the interviews

I aimed to end interviews on a positive note if possible, asking interviewees if they could talk about any positive aspects about their experience of breast cancer. I then asked if there was anything else they would like to discuss, and provided ample time for them to consider this before asking if they would be happy ending the interview at this point. After switching off the recording equipment, interviewees were informed that they could be provided with a summary of the findings if they wished, and all participants expressed an interest in this.

After leaving each interview, I made notes in my research diary, reflecting on the interview and how it had gone, and my initial thoughts on their account.

Ethical considerations

Ethical considerations were crucial when designing the study, and the research was approved by the Humanities and Social Sciences Research Ethics Committee (HSSREC) at the University of Warwick. The ethical considerations discussed below reflect the ethics central to the research, which were to remain sensitive and respectful, to avoid doing any harm, maintain confidentiality, and to make women's own experiences and perceptions central to the research, encouraging their active and informed participation and sense of control.

Sensitive and respectful approach

Crucial to the research, and in line with a feminist approach, the interviews were carried out with the greatest care to remain sensitive and respectful towards the interviewees.

Researching sensitive subjects such as the experience of a serious illness and its effects on a woman's perceptions of her body and identity, raises the potential for causing distress (Cannon 1989). Women were approached via organisations, support groups, or mutual

acquaintances with which, or whom, they already had a relationship. The women were encouraged to contact me directly via email or telephone, and if they did not respond after being sent the information sheet, I sent only one email gently reminding them about it. The interviewees were given the choice of where to be interviewed, and most chose their own homes, where they felt comfortable. I informed them that they could withdraw from the study at any point, including after the interview was conducted, and I reminded them of this again at the end of the interview. Topics which I judged to be particularly sensitive or difficult, such as the effect of breast cancer on their intimate relationships, were prefaced with a reminder that they were not obliged to talk about them.

If women became upset during the interview I made sure that they knew that we could stop the interview, take a break, or move on to a different subject if they wished. A number of the women became upset during their interviews, but none wanted to stop or take a break when offered, and I did not feel that any were highly distressed. I aimed to be a ‘sympathetic listener’ (Cotterill 1992:598), and took care to be sensitive in my responses to such emotional moments, offering sympathy and tissues, and allowing women enough time to be able to say what they wanted to say through their tears. Women often apologised for crying, and I tried to make it clear that this was not necessary (Cannon 1989). Throughout the interviews I aimed to create an atmosphere which was sensitive, encouraging, and non-judgemental.

At the end of the interviews I emphasised my gratitude to them for taking part, and I made sure not to leave too quickly to avoid giving the impression that I was in a rush to go after collecting data from them. I encouraged them to ask questions at this point.

The day following each interview, I emailed the participant to thank them again, and provided them with links to organisations which offer support and advice (Lewis 2003), namely Macmillan Cancer Support, and Breast Cancer Care. I also reminded them that they

could withdraw at any point, and encouraged them to contact me with any questions or further thoughts they had. I received positive responses from a number of interviewees, saying they had found the interview a positive experience, and some said that they would use the links to find advice or help.

Informed consent

The purpose of informed consent is that research participants do not feel obliged to take part, but rather volunteer with a full understanding of what their participation would involve, and what their accounts would be used for (Green and Thorogood 2014). Feminist researchers have scrutinised the concept of informed consent (Miller and Bell 2008; Oleson 2011), and consent has come to be understood as a process (Ellis 2009).

The consent process began before carrying out the interviews, and continued throughout the interviews. Before we met, the women were sent the information sheet and I informed them of what would be required of them and how long the interview was likely to take. Prior to beginning the interview, I asked women to read over a hard copy of the information sheet, and encouraged them to ask any questions. I also spoke with them about the aim and purpose of the research, and informed them about how their accounts would be treated. I made sure that they felt comfortable with their voice being recorded and transcribed, and reminded them that they could withdraw at any point. Throughout the interviews, I made sure women understood that they were under no obligation to answer any questions, or speak about any topics which they felt were too private or which they did not feel comfortable speaking about.

Anonymity and confidentiality

Maintaining anonymity was vital to ensure that the young women interviewed could not be identified and that the stories which they shared were confidential and treated with respect.

Participants were assigned pseudonyms before transcription, and any information (such as workplaces, dates, names of partners or children), which could reveal their identity, or the identity of others, were deleted or changed during transcription (Mason 2002). The consent forms were the only paper documents which contained their real names, and these were stored in a secure, locked store at the University of Warwick. I kept a spreadsheet containing participants' information on my computer and this was password-protected, and the demographic information sheets only contained pseudonyms. Audio recordings were deleted from the recording device immediately after being copied onto my computer, and all audio files were stored in a password-protected folder, and only named using the pseudonyms and date of the interview.

Some dilemmas regarding confidentiality arose. For example, during one early interview, the woman's husband intermittently came in and out of the room in which the interview was taking place. After leaving this interview, I was disappointed that I had not felt confident enough to ask the husband to leave, despite that the interviewee herself did not seem to mind her husband being present and even interacted with him while providing her account. Nevertheless, I made sure that before every subsequent interview I made it clear that we would need privacy. I also made the decision to interview this interviewee again a few months later as a result of this as I felt I had not been able to explore certain topics such as the impact on personal relationships and intimacy. Prior to her interview, one woman had asked if it would be possible to provide her with the audio recording and transcript of the interview. Given that I would be unable to ensure the confidentiality of an audio-recording, I informed her that I would not be able to provide this, but I could provide an anonymised transcript. The interviewee was agreeable to this, and consented to the interview.

Impact on the researcher

The impact on researchers carrying out sensitive research has been documented by researchers (e.g. Cannon 1989; Cotterill 1992; Hallowell *et al.* 2005). It has also been argued that it is important to share these issues, rather than exclude them from research description, and risk sanitising the account of the process (Ryan-Flood and Gill 2010). On a practical note, the task of getting to the participants' homes was often tricky and exhausting.

Carrying out the interviews had an emotional effect on me, both positive and negative. Interestingly, the moments I found most difficult were listening again to the interviews during transcription. During interviews it was possible to show sympathy and offer tissues and so on, but during transcription the sense of helplessness to alleviate the women's suffering was all the more powerful. To cope with this, I debriefed with my supervisors, and sometimes with a close friend, always ensuring anonymity. I found it important to take regular breaks during transcription, which can be fatigue-inducing in itself, but particularly when transcribing emotional interviews.

Many of the women expressed that their reason for taking part was to help other young women experiencing breast cancer, and therefore I felt a sense of responsibility to treat their accounts with the greatest respect. As Cotterill (1992) pointed out, one's ability to help participants in a practical way is limited, and to think that one might be able to, or that the women want this, is potentially a patronising approach to take. Instead, the researcher can only offer a sympathetic ear and try to use the information they provide in a productive and helpful way.

Data analysis

In order to analyse the data, the techniques outlined by Charmaz (2006, 2014) were drawn on. Suddaby (2006) argued that, in grounded theory studies, researchers sometimes make the

mistake of applying methods of analysis as if they were strict rules, rather than exploring different techniques to see what works best. Charmaz, too, encourages a creative approach to coding data, emphasising the inductive and interpretive dimensions of grounded theory (2014). Coding refers to “categorising segments of data with a short name that simultaneously summarises and accounts for each piece of data” (Charmaz 2006:43).

Transcription

Each interview was transcribed verbatim by myself, as soon after the interview as possible, so that data collection and preliminary analysis could be carried out alongside one another in line with grounded theory. I used software to slow the speed of the audio in order to transcribe verbatim, and also attempted to capture pauses or other non-verbal gestures which conveyed meaning. Transcribing the interviews as soon as possible also meant I was better able to recall gestures, facial cues, or other movements which were not audible in the recording. After initially transcribing, I listened to each interview again at normal speed while reading through the transcript. This allowed the correction of any mistakes and addition of any missed data, and also increased my familiarity with the data, enabling me to understand the interviews as whole pieces more closely.

Preliminary analysis

Once all of the interviews had been conducted and transcribed, I used QSR NVivo10 to support analysis, using grounded theory techniques set out by Charmaz (2006). I carried out preliminary analysis in order to think about how subsequent interviews could be improved, consider questions which were less fruitful, and identify topics emerging as significant. The preliminary analysis began during the transcription, when I made notes to myself about particular points to return to later, and then I began the process of coding the data in NVivo.

I utilised Charmaz's (2006) method of initial coding, which involves comparing data with data and asking particular questions of it, such as 'what does this piece of data suggest?' The aim of initial coding is to remain close to the data and to summarise processes rather than applying pre-existing theoretical categories to it. Charmaz recommends using 'action' language (2006:48), in order to code actions rather than topics. For example, I coded 'wanting to look like a normal woman for her daughter', rather than alternatively 'decisions about reconstruction'. This enabled the exploration of the processes which were evident in the data, rather than a set of topics. I also found it useful to use 'in vivo codes' (Charmaz 2006:55), which is to code segments in the women's own words. For example, I coded 'wanting to just get the breast off', and 'feeling like a strange little alien'. This enabled the women's own understandings and meanings to remain intact (Hesse-Biber 2014). In this phase of coding, Charmaz emphasises remaining open to alternative interpretations of the data, using brief labels for the codes, and moving quickly through the data.

I attempted to use the technique of line-by-line coding, whereby each line of data, regardless of whether they are full sentences, is coded (Charmaz 2006). However, I found that this fractured the women's accounts in an arbitrary way, and preferred to code the accounts in a way which made sense in terms of the women's own structuring of their experiences and perceptions. Charmaz also suggests coding incidents or events. For example, the use of codes such as 'first GP visit' proved useful. The experience of going to the GP with concerns about symptoms was present in almost all of the women's accounts, and using this method of coding meant that I was able to group all of their accounts of this together, and easily compare them in order to identify what was similar and different about the women's accounts of this particular phenomenon, and therefore what was distinctive about young women's experiences of it. After initially coding the interviews, I gathered codes together under umbrella codes such as 'feelings about body', in order to ease navigation of the hundreds of codes.

This initial coding phase was useful in becoming immersed in the data, beginning the analysis, and identifying areas of interest to pursue further in subsequent interviews. It meant that I became familiar with the participants' accounts and felt more immersed in the data, and also enabled me to take an iterative approach to the analysis.

Second phase of analysis

The second phase of coding set out by Charmaz, focused coding, produces codes which are “more directed, selective, and conceptual” (2006:57) than those produced in the initial phase. This involves sorting through and synthesising initial codes, and making decisions about which codes are the most significant, effective, and useful in building an interpretation of the accounts. Charmaz explains it as determining “which initial codes make the most analytic sense to categorise your data incisively and completely” (2006:58). The aim of focused coding is to compare large amounts of data and to allow ideas about it to emerge. To use the example from the previous section, using focused coding, I was able to compare all of the accounts of the first visits to the GP in each interview. Through this comparative process I developed an understanding of these events as biographically disruptive, and which had distinctive features as a result of the ages of the women (discussed in Chapter Seven). I considered how I had labelled particular segments of data and compared them with one another, considering which codes made the most sense, and which accounted for the data in a way which made the most sense in terms of the young women's own experiences and perceptions.

I found the actual process of this to be easiest away from NVivo. Using NVivo to collect segments of the data which referred to particular incidents, events, or areas of the women's lives, I converted them to a Word document which I printed in order to compare the data manually and take a fresh look. For example, I collated child codes under the umbrella codes ‘feelings about body’ or ‘being pregnant at diagnosis’ and compared all of the incidents in

which women had spoken about this. Some of these were extensive – there were dozens of child codes collated under ‘feelings about body’ – and being able to handle them on paper made it much more manageable. I made notes on the paper copies, or cut them up and grouped them together, making notes to myself throughout. NVivo was therefore used in this phase to collate codes, and the print-outs were used to further analyse the segments of data and compare the coding.

Third phase of analysis

The coding process was not a linear one, and the third phase of analysis occurred alongside and after the second phase. After the initial coding, I conducted another phase of coding during which I focused particularly on the parts of the accounts in which women spoke about their bodies and embodied experience. Rather than imposing pre-existing categories on the women’s accounts, the aim of this was to be able to focus on one particular area of my theoretical framework (although inevitably I spotted segments which were relevant to other parts of the framework and made notes). This allowed a more focused and attentive analysis of the ways that the young women experienced and perceived their bodies. I created a new codebook on NVivo which was solely focused on embodiment, and later used the same technique as described above to print off collections of codes and explore them on paper. After this approach proved useful, I followed the same method for the next part of the theoretical framework. I analysed the young women’s accounts, paying particular attention to how they talked about the impact of breast cancer on their life course, their futures, and their everyday lives. The research question was ‘to what extent does biographical disruption characterise the experiences and perceptions of the young women?’, but I aimed to allow alternative interpretations of the data to emerge rather than impose the framework of biographical disruption straightforwardly to their accounts. This involved comparing the segments of data and how they had been labelled, remaining critical to the coding and considering other possible understandings or explanations, and also exploring aspects of the

accounts which were different and contradicted one another. I followed the same method for the final part of the framework: gender and intersectionality. This involved again re-analysing the young women's accounts paying particular attention to the ways that gender and other oppression shaped them. Often this stage involved reflecting back on the earlier analyses, as gender had permeated the young women's accounts of the impact of breast cancer on their experiences and perceptions of their bodies, and on their life course.

This phase of coding was similar to Charmaz's (2006:60-63) account of 'axial coding'. It enabled the development of categories and subcategories, and an understanding of "the properties and dimensions of a category" (p.60). For example, the experience of uncertainty began to emerge as significant, and I was able to explore how the young women experienced the category 'uncertainty' across multiple spheres of their lives, and to identify how this was age-related (see Chapter Seven). It can also be viewed as the process of producing 'theoretical codes' (Charmaz 2006:63), which are described by Glaser (1978:72) as "weaving the fractured story back together". By comparing data across codes, developing the categories, and drawing links and comparisons between the categories and subcategories, relationships between categories emerged, and this created a broader picture of the young women's lives (Hesse-Biber 2014). For example, the relationship between uncertainty and the experience of everyday aches and pains emerged through the analysis, and a more coherent and whole understanding of the young women's experiences and perceptions could be constructed (see Chapter Nine).

Evaluating the research

There are ongoing debates within social science about the best approach to evaluating qualitative research. Some researchers are averse to using traditional concepts from scientific research, such as reliability and validity, and a number of alternative concepts have been developed, deemed to be more appropriate for qualitative research, such as authenticity, credibility, and transferability (Lincoln and Guba 1985; Creswell 2007). Cohen and Crabtree

(2008) noted that the search for a single set of criteria may be misplaced given that qualitative research is not a unified field. Validity and reliability may have endured as concepts in the field of health research because of its interconnectedness with scientific research which is located within a positivist paradigm, and, therefore, it is easier to conduct research in this area if traditional concepts are used (Cohen and Crabtree 2008).

To evaluate this research, I have chosen to use reliability and validity, in combination with reflexivity. I made this decision based on my view that the numerous alternative concepts which have been suggested, while they have illuminated the ways that qualitative research can be evaluated, ultimately refer to the reliability and validity of the research.

The meaning of validity in qualitative research

The concept of validity traditionally refers to the question: ‘did the study measure what it intended to measure?’ (Dyson and Brown 2006). In qualitative research, the concept of validity is discussed in terms of trustworthiness, authenticity and credibility (Lincoln and Guba 1985; Oleson 2011; Green and Thorogood 2014). Feminists have addressed the term, which some argue suggests that there is a single reality to be discovered, rather than reflecting the view of knowledge as situated (Oleson 2011). Lather (1993, 2007) has argued for the retention of the label validity, but to deconstruct what it signifies. Creswell (2007:206) argued that validity in qualitative research refers to “an attempt to assess the ‘accuracy’ of the findings, as best described by the researcher”. In other words, do the findings speak about what the researcher is claiming they do. This means that the reader must be able to understand how interpretations were arrived at (Mason 2002).

Validity in this thesis

In order to achieve this, the methods of data generation and analysis have been made explicit in this chapter. In addition, supportive evidence from the interviews is used in the chapters which follow, in order to demonstrate how the interpretations were arrived at, and I have also analysed deviant cases (Green and Thorogood 2014), accounts which did not support the interpretation, or which stood out as different. The use of the stakeholder panel increased the validity of the research and the credibility of the findings because it provided an opportunity for participants to offer their insights on the findings (Lincoln and Guba 1985; Green and Thorogood 2014). However, there are limitations to this method of aiming for validity, as discussed in the limitations section below. The regular discussions with my supervisors meant that I was challenged to make my interpretations explicit from the outset, and these assisted in considering alternative interpretations. In order to produce an interpretation of the findings which makes sense to the participants, and is therefore authentic and credible – criteria for validity – I remained close to the data throughout the analysis and aimed for a sense of immersion in the topic and in the participants' worlds (Charmaz 2006; Creswell 2007).

Maximising reliability in qualitative research

In traditional scientific research, reliability refers to the repeatability of a measure (Dyson and Brown 2006). However, from an interpretive perspective, research is seen as inductive, and the background, knowledge, and social position of the researcher are accepted as shaping the interpretation. Therefore, it is not necessarily expected that two researchers would come to the same interpretation of qualitative data (Green and Thorogood 2014). However, this does not mean that qualitative research should not be credible, and qualitative research is evaluated in terms of its employment of rigorous, transparent, and systematic procedures in the data collection and analysis, so that the research can be considered to be reliable (Creswell 2007).

Reliability in this thesis

I audio-recorded interviews and transcribed them verbatim, including pauses and words such as ‘um’ and ‘y’know’, which conveyed meaning. The use of the computer software NVivo meant I was able to manage large amounts of data in a systematic and transparent way. I submitted one example of an audio-recorded interview to one supervisor, and an example of a full (anonymised) transcript to both. Systematic, yet flexible methods for data collection and analysis were utilised, and these have been described in detail in this chapter in order to increase reliability.

Maintaining reflexivity

Reflexivity, a critical reflection upon how the position, background, knowledge of the researcher shaped the research, is regarded by many as an essential aspect of qualitative research (Green and Thorogood 2014), especially feminist research (Harding 1987; Edward 1990; Oleson 2011; Hesse-Biber and Piatelli 2012). Given that a feminist methodology positions women’s knowledge as arising from their subjective experience, the researcher must also be viewed in the same way. Rather than perceiving the researcher as a passive, objective, and distanced observer, a feminist methodology requires reflexivity. Reflexivity should permeate the entire research process (Hertz 1996; Hesse-Biber and Piatelli 2012). My own interests and background shaped the research questions and the theoretical framework. For example, my training as a social researcher with a particular interest in qualitative research meant that the research was situated within the interpretive paradigm. My interest in young women’s health and embodiment no doubt stemmed from my own social position as a young woman.

Oakley (1981) argued that by virtue of a shared gender, women have a common ground upon which the researcher-participant relationship can be built. This may be true to some

extent, but, as other researchers have highlighted (Razamanoglu 1989; Phoenix 1994), this is an essentialist view of gender, and there are aspects of identity which are not shared by all women, as well as structural barriers which result in diversity amongst women and which shape relationships and interactions in research. There were undoubtedly ways that my social position as a white, able-bodied, heterosexual, young woman studying at a university, shaped how I was perceived by participants, and the conversation in the interviews. For example, as a white woman interviewing minority ethnic women, I had to be mindful of the wider structural context of our relationship and the power dynamics present, as previous feminists have discussed (e.g. Barrett and McIntosh 1985; Edwards 1990; Phoenix 1994). This situation also presents structural and cultural barriers which impact on the shared meanings and understanding (Edwards 1990). For example, Tabitha spoke about the impact of chemotherapy on her skin and how this had particular meanings for black women (see Chapter Eight), and our discussion of this would likely have been different were I a black woman with shared knowledge and similar embodied experiences. This was also the case when interviewing lesbian women. For example, Vanisha spoke about the experience of health professionals assuming her heterosexuality and the impact of this (see Chapter Eight). When listening to her account, my own experiences of privilege in this context and the experiential distance between us came into focus for me, and I realised that it would likely have been a different conversation had Vanisha been interviewed by a lesbian.

A significant difference between myself and the interviewees was that I had not had breast cancer, and this inevitably impacted on the interviews. For example, some women may have wanted to protect me from the most distressing parts of their story (Miczo 2003). On the other hand many women used the opportunity to confide in me their fears and other distressing emotions. For example, Lyndsey told me that she had made a GP appointment because she was concerned about some bowel pain, something which she was not planning on telling even her husband unless she was sent for further tests. However, going into the research, I had imagined that being a young woman in my early twenties meant I would have

something important in common with participants, and I saw this as a strength of the research. I had not considered the gulf of experience which would become evident in some of the interviews despite this. Most of the women were older than me when they were diagnosed, and the age range of the women at interview was 28-52, so the oldest was almost thirty years older than me. The discussion during the interview therefore may have been influenced by this. My lack of experience with and knowledge of even a ‘normal’ pregnancy was obvious in the first interview I held with a woman who was diagnosed during pregnancy, and I endeavoured to learn more about what happens during pregnancy before subsequent interviews.

The possibilities, and ethical and methodological implications, of establishing rapport with participants in qualitative research have long been of concern to feminists (e.g. Oakley 1981; Stacey 1988; Cotterill 1992; Cannon 1989; Young 1997; Duncombe and Jessop 2008).

While some researchers have argued that the research relationship can be reciprocal, based on friendship (Oakley 1981; Denzin 1997), others have argued that this ignores the significance of social inequalities in the research encounter (Young 1997; Edwards and Mauthner 2008), and the moral dilemmas which emerge from developing friendships with research participants (Cotterill 1992; Duncombe and Jessop 2008). I was often amazed at the kindness shown me by the interviewees, even those who were struggling with the long-term effects of treatment or were balancing childcare still made time for me, offered to provide food for me, and even picked me up or walked me back to nearby train stations. However, there were other times when I sensed a great distance between myself and the interviewee, and I was not able to reach this level of rapport with them. One woman, for example, was herself experienced in conducting qualitative social research and, in combination with other differences between us, I found this interview to be very challenging as I felt anxious about saying the right thing. This highlights how the “balance of power is not fixed” in an interview, and varies according to the particular circumstances and age of the interviewee and researcher (Cotterill 1992:599).

Reflexive thinking about the presentation and behaviour of the researcher during the interviews can be found in previous research about the experience of breast cancer. For example, Crompton (2006) noted that she became self-conscious about her own breasts and the way she dressed during interviews. I too experienced this, and, further, found that interviewees directly compared their bodies with mine during interviews, in ways that sometimes made me uncomfortable, but which were powerful in conveying the distance which the young women with breast cancer felt between other women's bodies and their own. Rosenblatt (2006:55) wrote of her interviews with women with breast cancer: "[a]s we talk sitting face to face, the loss of her breast is also the potential loss of my breast". As a young woman myself, I became acutely aware that the women's stories were also potentially my story. I remember sensing this particularly when interviewing Naomi because when Naomi was diagnosed, she was the same age as I was at the time of the interview, a fact of which we were both aware during the interview, as she had asked me my age before we began.

Before undertaking the interviews, I myself was interviewed by a fellow researcher for a separate project at the University of Warwick. I volunteered for this mainly because I saw it as an opportunity to experience being an interviewee myself before conducting my own research. Although my research was about a much more sensitive topic than the project for which I had volunteered, I felt that this was a valuable exercise in helping me to empathise with interviewees.

Limitations of the research design

There were several limitations of the design of the research which I discuss in this section. Firstly, the sample had some limitations. The small size of the sample enabled an in-depth exploration of the participants' experiences, and a manageable amount of data, but it may restrict the generalisability of the findings. This is a limitation of any small, qualitative

study, but the method facilitates access to qualitative data, which is considered valuable “by the very nature of [its] subjectivity” (Kasper 1994:278). Sample size in grounded theory varies, but Creswell (2007) suggests at least 20. Therefore, given the constraints on myself as the sole researcher, 20 was deemed optimal. While it constitutes a relatively small sample, I was concerned about being able to give enough attention to each woman’s account during analysis, which would have been more difficult with a larger sample. I was also mindful that aiming to recruit more than twenty women might stretch the limited time resources, given that I was aiming to reach a relatively small group of women in the UK. The age range of the sample, while useful in establishing a group of women who were homogeneous in some respects, such as being pre-menopausal at diagnosis, also held some limitations. The life stage of women was vitally important in terms of how they experienced breast cancer, but the life stage of women in their twenties at diagnosis was often quite different to women in their late thirties or early forties. However, this meant I was able to explore, for example, the meaning of the length of treatment for women diagnosed at different ages, despite their similar hormonal status at diagnosis.

As well as the overall small sample size, I was able to reach only a small number of BME, lesbian, and disabled women, and I did not reach any women with learning difficulties. However, this is an improvement on much research in this area which has been conducted using a homogeneous group of white, heterosexual, and able-bodied women. Additionally, I was not able to sample women according to their particular socio-economic circumstances, given the constraints of the sample size and the priority placed on reaching minority ethnic and lesbian women. This is a limitation given that there is implicit evidence in the literature that younger women may be particularly affected by the financial impact of cancer (MacMillan 2006). Despite this, I was able to explore the impact of cancer over time in terms of the women’s financial situations, and I also gathered enough information to achieve a (limited) picture of their economic circumstances, by asking about their occupation, and using the Townsend Index of deprivation (see Chapter Eight).

It has been pointed out that recruiting participants solely through support groups may result in reaching women with similar experiences (Bell 2009), and this was part of the reason I decided to purposefully sample a range of gatekeepers in the hope of reaching women with diverse experiences. Inevitably, most of the women interviewed were similar in the sense that they were willing and able to take part, and felt comfortable speaking with a relative stranger about such personal experiences. However, I did note that it seemed to be quite a challenge for some of the women, and some even said that before they had breast cancer they would not have considered taking part in such an interview. In a sense, the interviews therefore reflected the changes which the women had experienced, and became part of their story.

While the stakeholder panel was a valuable way of checking my findings and receiving feedback on them from women who had experienced the phenomenon under study, this also had limitations. For example, it is not necessarily likely that research participants will analyse accounts in the same way as the researcher (Sandelowski 1993; Green and Thorogood 2014). The method has been criticised for being based on an assumption that there is a truth which can be established by checking interpretations with participants; a positivist assumption (Green and Thorogood 2014). However, the stakeholder panel provided an opportunity to explore how well the interpretations resonated with those who have experience of the topic under study, and this was consistent with grounded theory. Sandelowski (1993) argued that member checking can be problematic when members try to measure the findings against their own experiences and find that they conflict. I found that having three women on a panel rather than asking individual interviewees to comment on them, (a common form of member-checking (Creswell 2007)), meant that we could discuss diversity in experience and mitigate the effect of this.

The choice of method for data collection was one-off semi-structured interviews, which allowed for an amount of shared control over the interview, and the flexibility to explore

emergent issues. This method can help to avoid the ‘fracturing’ of experience which some quantitative and less open-ended methods of data collection can result in (Graham 1984). It also relies on what the women remembered and what they were willing and able to talk about, but this could be seen as a strength when the aim is to explore their perceptions. The use of a one-off semi-structured interview (or two interviews a few months apart in one case), rather than longitudinal methods, such as several interviews over time, meant that the accounts were a snapshot of a particular time. Other research such as Tighe *et al.* (2011) has utilised longitudinal methods, interviewing women several times over the first year since diagnosis. While this provided insight into the women’s experiences throughout treatment, and how their perceptions changed, the focus of my research was on life since completion of initial treatment. During the interviews, I was able to ask women to reflect back over their experiences and to think about how they felt at different points. A longitudinal approach also requires more time commitment from participants and stretches the time resources of the researcher. It has also been argued that some participants may find it easier to speak to a researcher who is a stranger rather than a friend or acquaintance (Cotterill 1992). Therefore, one-off interviews may have provided young women with an opportunity to speak to someone about their feelings knowing that we were unlikely to meet again.

The use of Charmaz’s (2006) grounded theory methods of analysis also had limitations. Firstly, as a novice researcher, I learned the best way to analyse findings as analysis progressed and, therefore, analysis perhaps took longer, as I ended up starting again a number of times and experimenting with different techniques. On the other hand, this likely increased my familiarity with the data since I spent so long being immersed in the analysis. The process of coding also occasionally felt frustrating as it meant having to separate complex parts of the women’s accounts in a fractured and arbitrary way. The coding practices which Charmaz (2006) suggests were variable in terms of their usefulness for this study, as discussed earlier. However, a strength of her version of grounded theory is that she presents them as flexible guidelines for practice, rather than strict steps to which the

researcher must adhere, as in earlier formulations of grounded theory. I felt able to experiment with different coding processes, and to find those which made the most sense and proved most useful in the analysis.

Conclusion

This research study was conducted within a methodological framework which privileged young women's own understandings of, and perspectives on, their experiences. Utilising a social constructionist grounded theory approach, and drawing on feminist principles, the study aimed to expand understanding of young women's experiences and perceptions, remaining sensitive and respectful towards the emotional state of the interviewees, and their accounts. The use of grounded theory techniques in data analysis aimed to achieve an interpretation of the young women's accounts which would resonate with their experiences.

The sampling method was informed by intersectionality, with the aim of reaching groups neglected in previous research. The final sample had limitations in that it included a small number of BME, lesbian, and disabled women. However, including their voices adds to the small amount of research about young women from these groups with a history of breast cancer. Three women in the sample were pregnant when they were diagnosed, an experience which is unique to young women, and this number is a strength of the sample as few women pregnant at diagnosis have been included in previous research. Although the sample of twenty is small, this meant that I was able to give each young woman's account considerable time and attention, something which I felt was important.

The use of a stakeholder panel strengthened the credibility and validity of research, as it enabled women who have experienced the studied phenomenon to contribute to the research, and to provide feedback on and insight into the findings. Inevitably, the democratic nature of the study is limited and the balance of power is always in favour of the researcher, but the use of a stakeholder panel and the method of data collection were intended to increase the

participatory nature of the study. I privileged the young women's accounts, by supporting them to tell their story as they wished as much as possible. I hoped to achieve this through maintaining sensitivity to the young women throughout the interview, and by remaining flexible towards my interview schedule.

The data analysis was conducted drawing on techniques set out by Charmaz (2006) for social constructionist grounded theory. Some of these techniques proved more useful than others, and I was able to develop my own approaches using the guidance of Charmaz's suggestions for principles and practices rather than the more prescriptive methods laid out by Glaser (1978) or Strauss and Corbin (2008).

This chapter has described and evaluated the methodology underpinning the research, and the research design, demonstrating how I aimed to answer the research questions which were developed from the literature review. In the following four chapters I analyse the findings which were reached using these methods.

Chapter Six – Young women at odds with their bodies: Embodied experiences and perceptions of living with a history of breast cancer

Introduction

The following three chapters contain the analysis of the young women's accounts, exploring, in turn: the impact of living with a history of breast cancer on young women's embodiment; the significance of biographical disruption; and the influence of gender and other intersecting oppressions. As I have demonstrated in the previous chapter, the women's own perspectives are central to the research, and the analysis is grounded in their accounts.

In this chapter, I explore the ways that living with a history of breast cancer impacted on young women's experiences and perceptions of their bodies, and how they made sense of and managed the physical changes caused by treatment. As argued in Chapter Two, the process of embodiment can be understood as constitutive of experience and identity, rather than the body being simply being an object which is acted upon by external forces. This chapter is structured according to two major themes which emerged from the women's accounts: embodied risk and dissonance. Following these there is a section which explores the accounts of the women in the study who had gone through the profound age-related embodied experience of being diagnosed while pregnant. I first explore how the data provides evidence that young women were living with 'embodied risk' (Kavanagh and Broom 1998), and that there were particular ways that their age and life stage at diagnosis shaped their experience of this. I then consider the ways that the impact of treatment resulted in a dissonance which women experienced between their bodies and their own and others' expectations of their bodies. In the final section, I explore the accounts of the three young

women who were diagnosed during pregnancy and the bodily experiences and perceptions which this resulted in.

Young women living with embodied risk after breast cancer

The first key theme in this chapter is the phenomenon of young women living with ‘embodied’ or ‘corporeal’ risk (Kavanagh and Broom 1998) after initial treatment for breast cancer. As discussed in Chapter Two, embodied risk refers to the way that individuals may perceive a risk to be located within their own body. During the interviews and analysis, living with the fear of recurrence emerged as a significant theme in the young women’s accounts. This is not surprising given that existing research has identified the importance of fears about recurrence (e.g. Dunn and Steginga 2000; Allen *et al.* 2009; Adams *et al.* 2011), but analysing this within the framework of embodiment, highlighted that they experienced risk as inherent within their bodies, and that this profoundly shaped their experience and understanding of their bodies.

Young women’s experiences and perceptions of embodied risk

This section explores the young women’s accounts of their experiences and perceptions of their bodies, providing evidence that they experienced embodied risk. Previous research has identified embodied risk in women with abnormal cervical smears (Kavanagh and Broom 1998), or women at high risk of breast cancer (Robertson 2000), but it has not been used to explore the experiences of women living beyond breast cancer treatment. The language used by many of the women illustrated that, despite treatment which was considered successful, cancer was viewed as still hiding within their bodies.

“For all I know my cancer could still be there, like a tiny little cell that one day will explode but I’m never gonna know.” – Melanie

“I think there’s a bit of a thing of not knowing if it’s gone really, I think there’s an element in my head of worrying if it’s still there lurking.” – Dawn

This contributed to a sense of distrust of their body which was perceived to be potentially harbouring an enemy within its “secret unpredictable interior” (Crouch and McKenzie 2000:196). In Chapter Two, I argued that bodily reminders may contribute to a sense of embodied risk. For the women in this study, aches and pains which would otherwise have been seen as innocuous were experienced as potentially cancer.

“I think before if you had a headache you think ‘Oh I’ve got a headache’ or if your foot’s hurting you think your foot’s hurting, whereas now I tend to think ‘Oh is that cancer? Has it come back?’” – Sarah

Living with embodied risk after breast cancer for many of the young women involved living with the risk perceived to be located within the remaining breast or breast tissue. Women who had lumpectomies described changes to their breast tissue which occurred as a result of surgery, and this inhibited the young women’s ability to feel confident that they now knew their breasts.

“When I check for lumps, it feels completely different to how it used to feel because there’s a lot of scar tissue I guess, and so the whole feel of the breast is completely different.” – Evelyn

“There’s so much lumpy scar tissue that you can’t recognise a good lump from a bad lump so it’s like how am I meant to recognise it?” – Lyndsey

A recent study (Khan *et al.* 2010), examined a large dataset to explore patterns of cancer screening attendance in the UK, finding that women previously diagnosed with breast cancer

were 22% *less* likely to receive a mammogram compared with their matched controls. The authors excluded women who had had a double mastectomy so this could not explain the difference. Accounts from the women I interviewed indicated that Khan *et al.*'s apparently surprising finding could be related to fear. Kavanagh and Broom (1998) argued that, through medical surveillance (cervical smears in the case of their study), the body is "continually produced as a source of danger to the subject" (p.440). The young women in this study were balancing, on the one hand, their perception of their bodies as a source of danger, and on the other hand, the profound anxiety which arose around the time of annual check-ups. Evelyn, for example, described the "*cycle of anxiety*" which she and her partner experienced due to her annual mammogram. None of the women I interviewed indicated they would not attend their annual screening, but it was seen as a particularly anxiety-inducing time, and, from the interviews, I could understand why some women choose not to go for screening.

"It never feels like it's gone away, it never feels it, even though you know that lump isn't there anymore, it's always that y'know that fear that it's gonna come back. And they say to you about checking your breasts and things and you do it but you do it tentatively because you're bloody terrified of finding something else." – Charlotte

On the other hand, Sarah checked herself almost obsessively.

"The last oncologist I saw um I said 'I check my breast every day' ...He goes 'That's a bit much, don't you think?' ...But I still sometimes tend to sit down and do this [feels for lump] with the other one and across the scar, can't help it." – Sarah

Most of the women who talked about BSE described performing it tentatively and without confidence in their ability to find a new lump, particularly in breasts with lumpectomy scars and resulting scar tissue. The women felt heavily reliant on medical knowledge to define them as being healthy or ill, as having cancer or not, highlighting that living through the

experience of breast cancer may mean not only losing trust in one's own bodily knowledge, but also surrendering a level of autonomy of the body to medical professionals and conforming to medical regimens. Yet, after the end of initial treatment, the young women were confronted with the realisation that medical knowledge was limited in its ability to define them as cancer-free.

“No one scans you and says ‘You’re alright now’, they just say ‘We think the treatment we’ve given you should kill any cells that are possibly stray’.” - Lyndsey

“It’s not spread as far as I know, at the moment they say it’s nothing – ‘No evidence detected’ they say at the minute.” – Beverley

As has been previously noted (e.g. Klimmek 2012), after cancer treatment, people enter into a stage of watchful waiting. This fundamentally shaped the young women's experiences and perceptions of their bodies after breast cancer. The combination of the loss of trust in bodily knowledge, the persistence of bodily reminders, and the limitations of medicine, resulted in a state in which the young women came to view their bodies as threatening; harbouring and hiding a potentially lethal cancer cell. The women therefore experienced what can be understood as embodied risk.

Dimensions of embodied risk related to the women's age and life stage at diagnosis

This perception of their bodies as inherently risky was related to their age and life stage at diagnosis. All of the young women interviewed had been pre-menopausal at diagnosis, and a large number of them were hormone receptor-positive. Eighteen of them were, as a result, receiving long-term hormonal treatment, such as Tamoxifen, as a preventative measure. Consequently, many of the young women viewed hormonal changes, such as the return to a pre-menopausal status, or becoming pregnant, as dangerous.

“If they’re telling me they wanna suppress my ovaries because the tumour was fuelled by hormones, if my ovaries restart [after ovarian suppression treatment ends]...Does that mean that there’s more hormones now flying around again?” – Beverley

“A few people offered to be a surrogate for us [but] I would have had to have all the hormones and my cancer was fed on hormones so why would I want to have more hormones put into me to potentially make it come back?” – Kim

For some women, the side-effects of the long-term hormonal treatment, and ovarian suppression, were sometimes viewed positively:

“It is your ovaries going to sleep that are making you ache...It doesn’t get me down in the dumps ‘cause I’m happy to be here to be quite honest...I think ‘Well it’s doing its job and I’m here’.” – Beverley

The side-effects were seen as evidence that the treatment was working, and therefore that they were less at risk for recurrence. For these women, reducing their risk meant preventing their bodies from returning to a pre-menopausal state, or from becoming pregnant. The implications of this for the women’s life course are discussed in more depth in Chapter Seven, but it is important to note that this also shaped how young women experienced and felt about their bodies after treatment.

Another way in which age was salient in young women’s experiences of the risk of recurrence was related to the many decades which they were facing ahead during which cancer could recur.

“Everyone sort of like I know that’s ever had cancer...If they don’t die from it when they first get it, either it comes back or they end up getting a different type of cancer like however many years on. So I kind of like think like, because I was like 22 when I was diagnosed I think, y’know, ‘What’s a nice age to live to? I guess like 82’ and I kind of always said to myself ‘Am I really gonna go sixty years without getting cancer again?’” – Faith

Faith’s account demonstrates powerfully and poignantly the significance of age to young women’s lives with embodied risk after breast cancer.

Three women in the study (Dawn, Vanisha, and Faith) had undergone contralateral prophylactic mastectomy (CPM), another woman (Charlotte) was in the process of setting a date for her surgery, and several more of the participants talked about having asked their consultants about their eligibility for the surgery. CPM is the removal of a breast which does not have cancer, in order to prevent cancer from developing in that tissue, as discussed in Chapter Two.

“I did ask to have a double mastectomy and got told ‘No that wasn’t necessary’. So that’s probably maybe once a week I have a look at good booby and I think ‘I hope you don’t let me down’. I don’t want to go through that again.” – Tabitha

A number of studies (e.g. Jones *et al.* 2009; Tuttle *et al.* 2007; Yao *et al.* 2010; King *et al.* 2011) have found that younger women are more likely to opt for CPM, yet there is very little qualitative research exploring the meaning of CPM to young women living with a history of breast cancer. Charlotte’s account of her decision demonstrates the relevance of the concept of embodied risk in understanding the young women’s perspectives on preventative surgery:

“Losing my breasts is a massive thing really and given a choice I would clearly not want to be doing it, but I can’t spend, really I don’t feel like I could spend the rest of my life looking over my shoulder and thinking ‘Has the cancer come back?’” –

Charlotte

The radical surgery had implications for Charlotte’s mobility, given her physical impairments and reliance on her arms to move around, but the threat of recurrence was a powerful one, especially in the context of Charlotte’s strong family history of cancer, and her BRCA mutation.

Given the accounts in this chapter, it should not be so surprising that many young women choose this option. It seems that the risk of recurrence, for some women, trumped the benefits of keeping both of their breasts. However, as Faith’s earlier account demonstrated, despite having had CPM, she still lived with the fear that she would experience cancer elsewhere in her body. The sense of a risk was therefore not straightforwardly overcome through CPM. The young women felt profound distrust of their bodies, and a sense of responsibility to do everything they possibly could to prevent recurrence, contemplating the many decades ahead of them during which cancer could recur. Managing the risk of recurrence for the young women therefore involved managing their bodies, and can be seen as an ‘embodied enterprise’ (Robertson 2000:230).

Many women are unable to access such surgery because they do not have a family history, an identified BRCA mutation, or enough money to have private treatment. Beverley felt frustrated when the results of her genetic test came back negative for BRCA mutations, because it meant she could not get a preventative mastectomy and oophorectomy through the NHS. As a result of this, she had made the decision to have reconstruction, and her account revealed that her fear of recurrence was central to this decision.

“My surgeon has said he will take some of the tissue from this [unaffected] side to reduce it, so in my own head if it’s smaller, if my boob’s smaller, there’s less risk...He can’t take it off, but he’ll reduce it for me.” – Beverley

Beverley told me she would have ideally chosen CPM with no reconstruction, but choosing reconstruction was the next best thing, as it meant that some of the risky breast tissue would be removed.

In the interviews, I felt the sense of fear which the possibility of recurrence generated for the young women, especially those whose treatment had been particularly difficult. The long-term effects of treatment were still ongoing, and the thought of going through treatment again, especially chemotherapy, was more than some of the women could bear. This fear shaped the young women’s embodied experiences and perceptions after initial breast cancer treatment, and their decisions about preventative and reconstructive surgery. I now turn to how this sense of their bodies as risky was experienced in interactions with others.

The body and risk in young women’s interactions with others

A significant point which many of the women wanted to emphasise to me during the interviews, was that breast cancer did not only affect them, but also those around them. Their accounts revealed that their perceived sense of risk of recurrence as located within their bodies was also experienced by others and within interactions with others, which is something that previous research has not explored.

“Just as I’m aware that I could get a recurrence, I imagine my sister is, and other people.” – Vanisha

Others around the women also reinforced their sense of risk by monitoring any aches and pains they had, or by governing their behaviours deemed as risky. For example, Gemma

described her husband as being “*constantly on my back*” about any aches or pains she had.

Evelyn said similarly:

“Every couple of weeks [partner] will say something like ‘Are you alright, have you checked yourself?’ or ‘You shouldn’t be eating that chocolate bar’ or something.” –

Evelyn

Evelyn also described how the positioning of hormones and pregnancy as dangerous impacted on her sexual relationship with her partner.

“We had to swap to using condoms...I really miss that side of things...There’s one thing it has changed is that [partner] is absolutely terrified of getting me pregnant.”

– Evelyn

This could be reinforced by health professionals. For example, Faith described how her health providers had ‘whipped out’ one of her ovaries unnecessarily following a (false) ovarian cancer scare.

“I asked about egg freezing but he [surgeon] was just like ‘Well would you want to keep eggs from a dodgy ovary?’” – Faith

The young women’s bodies as risky were therefore experienced and perceived in interactions with others and impacted on the young women’s relationships. This was also informed by the significance of hormones and the young women’s status as pre-menopausal at diagnosis.

Not all women experienced embodied risk

Not every woman I interviewed seemed to be living with embodied risk, or at least risk seemed to be less prominent in some of the young women's accounts. Mehnert *et al.* (2009) explored the frequency of fear of cancer recurrence in women with a history of breast cancer using quantitative measures, finding that it was higher among women who received chemotherapy. In my research, which was not statistically representative, risk was less salient in the accounts of Olivia and Joanna, both of whom were told that chemotherapy was optional for them, and both chose not to have it. I asked Olivia if she worried about recurrence and she said:

“No I don’t. Um I guess yeah I’ve never regretted the decision not to have chemotherapy... I’m just gonna make sure that like I keep having regular mammograms... That’s all I can do really.” – Olivia

It is possible that Olivia minimised the risk of recurrence to reconcile her decision not to have chemotherapy. Olivia made this decision in the light of having seen a close friend suffer through the treatment. This supports Hallowell's (2006) contention that seeing another person endure suffering forms part of the experiential knowledge which shapes people's responses to risks.

Joanna also chose not to have chemotherapy, in large part because she was concerned about its effect on her fertility and having children was extremely important to her. Joanna was also aware that the limits of medicine to define her as cancer-free would apply whether or not she had chemotherapy:

“You can’t ever be given a ‘You are all in the clear’” – Joanna

In contrast, Catherine did have chemotherapy, but she was not very concerned about recurrence, instead placing great confidence in medical treatment and health professionals.

“I believe her [consultant] when she says I’d be unlucky if it came back.” –

Catherine

Catherine’s mother had been treated for breast cancer a number of years previously, and had not experienced a recurrence, and she talked about how this had shaped her perceptions.

“My mum had breast cancer so my parents were quite sort of, well not relaxed about it, but they know that you can have treatment and get better, and also seeing someone do that and yeah be fine with it.” – Catherine

This suggests that the young women drew on their biographical and experiential knowledge, as well as medical knowledge, in order to make sense of living with risk.

On the other hand, Evelyn chose not to have chemotherapy, but risk was a very strong theme in her account, and she had made dramatic changes to her lifestyle and diet in order to prevent recurrence.

“I feel responsible for trying to keep myself as well as possible but I don’t know how to do that so I’m kind of taking in as much information as I can in the hope that if I try and do a bit of everything it’ll help.” – Evelyn

Further research is required to investigate possible explanations for the differences between women who did and did not experience embodied risk and why, or if, fear of recurrence is connected to the experience of chemotherapy. It might be that being told that chemotherapy was required increased the young women’s perceptions of cancer having spread further into

the body, and therefore potentially remained, lurking. Being told that chemotherapy was optional (as in Joanna and Olivia's case) may have made the women feel more secure that their cancer had not spread and that they would not experience recurrence, although Catherine and Evelyn's accounts challenge this. The suffering involved in the experience of chemotherapy may also have increased the women's sense of vulnerability in their bodies, as well as increasing the fear of recurrence which might result in another experience with chemotherapy, something which the women desperately wanted to avoid. It also appears that the women drew on experiential knowledge of others' experiences of cancer to make sense of their own embodied risk.

The finding that young women experienced embodied risk, and that this was related to their age at diagnosis, extends current knowledge about the experiences of young women living beyond breast cancer, and about how individuals understand and experience risk. It also prompts questions about why risk was more prominent in some women's accounts than others, and how to alleviate it, opening up avenues for further exploration.

Dissonance between the reality and expectations of young women's bodies

The second major theme which emerged from the young women's accounts was the dissonance which women experienced and perceived between the age-related expectations of their bodies and the current reality. This was largely due to the physical changes wrought by treatment on their bodies, and the implications these had for their everyday lives. The analysis demonstrates that these bodily changes resulted in the perception of a gap between how they imagined their bodies should feel, look, and function at their age, and the reality. In the following sections, I first present a table which shows the multitude of effects which the women described as a result of treatment, and which were ongoing. I then draw on the accounts to discuss a number of areas in which the women experienced a dissonance between their expectations and the reality of their bodies: the impact of treatment-induced

menopause; the significance of changes to sensation and physicality; and the impact on young women's sexuality.

The ongoing physical effects of treatment

Table 4 below shows the physical effects of treatment which women described to me, and the causes to which the participants attributed them. Not every participant experienced every effect; some mentioned very few, while others described experiencing nearly all of them. Women experienced a multitude of side-effects of treatment while going through their initial treatment, but this table highlights those effects which were ongoing or permanent.

Table 4 - Long-term effects

Effect	Attributed causes
Weight gain	Steroids during chemotherapy
Changes to body shape	Treatment-induced menopause
Hair loss and long-term scalp issues	Chemotherapy; Tamoxifen
Dry skin	Chemotherapy; Tamoxifen
Lymphedema (swelling of the arm)	Lymph node surgery
Scars to chest, back, stomach, and indentations to breasts	Surgery
Formation of fatty tissue in breast	Lumpectomy
Radiation tattoos	Radiotherapy
Back pain and loss of strength	Reconstructive surgery
Joint aches and pains; osteopenia (precursor to osteoporosis)	Treatment-induced menopause
Numbness	Surgery to breast, chest, back, abdomen, armpit
Neuropathic pain	Radiotherapy
Vision problems	Tamoxifen
Absence of menstrual cycle	Treatment-induced menopause
Hot flushes	Treatment-induced menopause
Changes to cognitive ability e.g. memory impairment	Chemotherapy; treatment-induced menopause
Depression, mood swings	Tamoxifen; Zoladex; the emotional impact of treatment
Fatigue	Chemotherapy; Herceptin; Tamoxifen

This table provides an insight into the numerous ongoing physical changes which the young women described to me during the interviews, and demonstrates the profound and far-reaching impact of treatment on their bodies.

Treatment-induced menopause

Several treatments for breast cancer can induce menopausal symptoms, including: chemotherapy; ovarian suppression such as Zoladex (to prevent damage to ovaries or as a preventative measure after initial treatment); and long-term preventative hormonal treatment such as Tamoxifen. The onset of treatment-induced menopause had particular implications for young women planning their families, and this is discussed further in Chapter Seven. However, as well as the impact on their childbearing plans, these effects also shaped their everyday lives, and produced a gap between the expectations and reality of their bodies. Women held assumptions about what kind of bodies they should have at their age and life stage, and menopausal symptoms, such as fatigue and hot flushes, contradicted this, and were experienced by the women as sudden and premature ageing.

“I think when you go through the menopause naturally, if you do it at the right time, you’ve probably started slowing down anyway...My depression, my weight gain, my energy: it was as if somebody had flicked a switch.” – Olivia

“When you get to 50 it’s normal like everyone goes ‘Oh menopause, give her some extra time’...It wasn’t how it was supposed to be, y’know, as a 30-year old.” – Joanna

The effects of treatment-induced menopause shaped their everyday lives. For example, the joint aches and pains were experienced as bodily reminders.

“I feel heavier and my joints hurt, I’ve got more pains in my body than I used to have.” – Sarah

“I’m always reminded when I get out of bed in the morning ‘cause I get out of bed, hold onto the wardrobe to get myself up and plod into the bathroom and then I have to come down the stairs one at a time.” – Beverley

And these were also experienced as premature ageing:

“...Feeling like an old granny. My joints are now really bad.” – Lyndsey

The young women therefore found that their bodies became restrictive in terms of living the everyday lives which they expected at their age, and they felt a dissonance between the body which they and others expected, and the one which they actually had.

Sensation and physicality

As I argued in Chapter Two, previous research has often focused on appearance to the neglect of sensation and physicality when exploring the experiences of women living beyond treatment for breast cancer (Thomas-MacLean 2005). This reflects patriarchal norms which place a woman’s appearance at the centre of their overall worth, and privileges others’ experiences of women’s bodies over their own. It also reflects a definition of body image which does not go beyond appearance. In an attempt to avoid this, and to make women’s experiences central, I asked women if they could talk about how their body *felt* since treatment, which yielded important insights into the impact of treatment on their embodied experiences. In this section I discuss: the women’s accounts of numbness and altered sensations after surgery; back pain and strength; asymmetry; bodily coherence; and weight gain. This is not to suggest that the impact of treatment on appearance was not significant for the young women. Accounts of sensation and appearance were often interwoven in their responses, highlighting that experience and perception of these phenomena are not always separable in women’s everyday lives. However, prompting the women to talk about how

their bodies felt yielded some important insights into the impact of treatment on their embodiment.

Most commonly, women described numbness of reconstructed breasts, and around the surgery scar, and sometimes in the whole area.

“There’s not an awful lot of sensation in them...If someone were touching them I could feel that they were being touched but not anything else really.” – Dawn

Reconstructive surgery often involves moving skin and tissue from other parts of the body, usually the abdomen or back, and this resulted in strange sensations for the women.

“With my tummy I’m numb on the inside but I can feel the outside, and with my boob it’s like I’m numb on the outside but I can feel the inside, it’s kind of quite strange.” – Ailsa

*“Sometimes we play a game called ‘boob or back’ and my husband prods me and it still feels like my back muscle sometimes, ‘cause it technically is...It’s really weird.”
– Kim*

These sensations affected women’s everyday lives as they found themselves with a body which suddenly felt very different, and this was sometimes experienced as reminders of their treatment.

“If someone hugs me I’m like ‘Ooh that hurts’ and it doesn’t hurt at all but I think it’s just from the scar tissue.” – Melanie

“It’s only now, it’s been two years, three years, and it’s only now that I feel a bit more comfortable lying on my front because otherwise it feels really weird.” – Kim

“The right side is a lot harder and sometimes, ‘cause I sleep on my front, if I’m not in the right position I think ‘Oh for goodness sake I just want to get comfortable’, so that can remind me.” – Philippa

For Beverley, the numbness in her mastectomy area was viewed as a good thing because it meant that wearing her prosthesis was more comfortable. In contrast, Ruth experienced quite serious neuropathic pain on her affected side and said that this sometimes made wearing her prosthesis uncomfortable.

Women who had the type of surgery which involved transferring muscle, skin, and fat from their back around to their chest (LD flap), often described back pain and loss of strength.

“[When] I climb, before if I was gonna slip I knew, but now if I can’t hold it it’s a case of – I don’t get the ‘Oh I’m gonna drop soon’ it’s ‘Oh I’ve gone’. I can’t hold on.” – Kim

Symmetry was viewed as very important. Women who had not undergone reconstruction talked about feeling asymmetrical and the discomfort which this caused.

“I would like to have either two boobs or no boobs. I don’t know how to explain how I feel...Probably just a bit lopsided, is probably the word.” – Beverley

But women who had had a single reconstruction also sometimes felt a sense of unevenness and asymmetry:

“If I jump up and down, one side jiggles the other side doesn’t, it’s just really odd.”

– Olivia

Dawn said that she was happy with the appearance and feel of her reconstruction, even down to the way they ‘wobble’, highlighting that appearance and sensation are interrelated.

Surgery also resulted in women feeling different within their bodies in terms of bodily coherence. Hayley vividly described her sense of an altered body after her mastectomy and reconstruction:

“I was really aware of the fact that I’d had a mastectomy every day, maybe multiple times a day. It felt unnatural y’know your limbs all join together very naturally you don’t think ‘Oh this part of your leg’s attached to this part of your leg’ or ‘Your hand’s attached to your arm’, it just flows. And with the reconstruction and everything...Just felt very false in terms of, not in terms of emotionally, but physically...I just was constantly aware of the fact that there was a part of my body that had been messed around with and adapted.” – Hayley

Although Hayley said this was improving, she still felt this sense of discomfort in her altered body, almost two years on from her diagnosis. On the other hand, some women described integrating the surgical changes into their sense of bodily coherence.

“Women just, they grow to love them [reconstructed breasts] and it just becomes part of them and they don’t even think about it anymore...It definitely has kind of become a bit like that...It’s just part of my body.” – Ailsa

These alterations to the “physical terrain of their bodies” (Davis 2008:67) affected the everyday lives of the young women, and shaped the way they interacted with others. For

example, Sarah described her technique of hiding her breast loss when without her prosthesis:

“If somebody comes [to the door] I don’t run upstairs now to look for it I just have a habit of doing this [drapes arm across affected side] over when I’m talking to someone.” – Sarah

When I asked young women how they felt about their bodies since treatment, one of the most commonly mentioned issues was weight gain and changes to body shape. This was often talked about as more significant than, for example, breast loss, as two women who had had mastectomies without reconstruction illustrated:

“I’m quite comfortable with the way I am, I’d like to lose weight and be back to the size I was but with regards to having an operation to make me have two breasts rather than one, I don’t think it’s really, I’m not that fussed.” – Gemma

“I’ve put on a stone or two during my treatment and I’m more fussed about the [way the] whole of my body looks ‘cause of the weight gain than I am about all the scars and stuff.” – Beverley

The young women related these changes to the alteration of fat distribution and shape of their bodies, which they attributed to hormonal changes and onset of treatment-induced menopause.

“My shape changed as well and that was really, really difficult for me. ‘Cause I’ve always been like, I’ve always been a real hour-glass shape.” – Olivia

Breast cancer and its treatment, therefore, affected a particular dimension of embodiment: sensation and physicality. These new and strange sensations resulted in the women experiencing their bodies in a way that was difficult to reconcile with their expectations of their bodies. They expected, for example, their bodies to be able to tell them where they were being touched, but the impact of surgery prevented this.

The impact on young women's sexuality

During the interviews, women often volunteered information about the impact of treatment on their sex lives, and most were happy to discuss it when I sensitively approached the topic. Their accounts showed that physical changes and menopausal symptoms impacted on their sexuality, and they had to navigate sexual experiences with a body which did not match their own or others' expectations of a young woman's body. A number of the women spoke about the strange feeling of simply having no sexual desire, illustrating that their bodies were not conforming to the experiences which the young women had previously had.

"It's really bizarre...It's just not there and y'know you sort of think 'Oh well maybe I'll feel it at some point if I watch something or I read something' and you just, it doesn't happen and it's like 'That's really, really strange'." – Gemma

"It's weird because...It's not like I'm thinking 'Oh I wish I wanted to have sex more', 'cause you just don't care.'" – Olivia

"In my head I'm like 'I really fancy you I'd like to have sex with you now', but my body's like 'Get the hell away from me'." – Naomi

In a systematic review of the literature, Gilbert *et al.* (2010) found that women who undergo chemotherapy are more likely to report sexual dysfunction than women who do not have chemotherapy, and that this is the most significant factor in determining sexual problems

after breast cancer treatment. While my sample is not statistically representative, this pattern was supported by my findings. Of the five women in the group who did not have chemotherapy, only Olivia reported a loss of libido, and it is possible that this was related to the depression which she experienced after the end of initial treatment and was still being treated for. Women who did not have chemotherapy did, however, describe menopausal symptoms, such as vaginal dryness, as having an impact on their sexual functioning, as did women who had had chemotherapy.

Despite chemotherapy being thought to be the most important factor, most of the women blamed Tamoxifen, rather than chemotherapy, for their loss of sexual desire.

“The medication has completely annihilated my sex drive – the Tamoxifen – I’ve got pretty much zero... I just wanna come off my Tamoxifen because I’m kind of losing identity a little bit with it.” – Gemma

The evidence about a link between loss of sexual desire and Tamoxifen is contradictory (Gilbert *et al.* 2010), but women were hopeful that once they finished this medication, their sex lives would return to normal.

As discussed in Chapter Two, when understanding women’s sexuality after breast cancer, the impact of treatment on a woman’s body and her sexuality must be located within a social and relational context Gilbert *et al.* (2010). The accounts of the young women in this study support this. Some women felt that breast cancer had not had an effect on their sexuality. For example, Faith said that, because she had small breasts, *“it wasn’t like a big sexual sort of feature to me anyway”*. Joanna said that she was not willing to *“go there with [her] thoughts”* and found that her sex life improved when she finished her Tamoxifen and she and her husband began to try to conceive, highlighting the relationship between sexuality and fertility for young women after breast cancer.

“We have other things on my mind like ‘We’re gonna make a baby!’” – Joanna

For Philippa, her sex life improved after the treatment, which she attributed to leaving her abusive husband soon after treatment, and finding a new partner. She described her first sexual experience with a new partner after treatment:

“Actually it was kind of empowering because I thought ‘Y’know what? Yeah, I’ve had breast cancer, but I can still do this and I can do it with you because I’m not married anymore!’” – Philippa

Kim described an altered perception of her breasts, which shaped her sexuality. She said that she did not always see her affected breast as a ‘boob’, and this was her response when I asked what she saw it as:

“Dunno. Nothing sexual. I don’t consider it anything sexual...To me it’s my back muscle, it’s a silicone implant in the shape of a boob in the right place...It’s not that I don’t want to be touched or anything like that but I’m like ‘What’s the point? There’s one there, the real one, one’s a fake, do you need to go anywhere near them really? That one tried to kill me.’” – Kim

Kim found that she could no longer see her breasts as anything sexual, and part of this was related to her sense of betrayal by her body.

These accounts illustrate the diverse responses, and that the women’s social and personal circumstances, as well as their personal meanings about their breasts and sexuality shaped the young women’s experiences and perceptions of sexuality after breast cancer. These accounts must also be situated within the context of gender relations and meanings of femininity, as discussed further in Chapter Eight.

Only one woman in the sample – Melanie – was single at the time of diagnosis. Being single, however, was a salient issue for the group as a whole, and many said that the whole experience of cancer would have been more difficult had they been single, citing having to reveal their altered bodies to new partners as a significant reason for this. The following quote from Sarah is typical of the older or married women in the sample:

“There’s somebody ten years younger than me who’s not been married, who’s not got children, who’s got to go through a relationship explaining ‘I’ve got one breast’ or ‘That one can’t feel anything, it’s there but it’s a dead breast I can’t feel’ ...So even when I was going through the worst I just looked back at them and think ‘Actually, you’re not going through the worst’.” – Sarah

Melanie was single at the time of our interview, five years since her initial diagnosis and treatment, and she described the difficulties of entering into new sexual relationships after treatment.

“For so many reasons, I mean, like, where to begin? Like my hair for starters, I think if anyone goes near me I flinch a bit I’m just like ‘Oh don’t touch me’ whereas I never used to be like that...I now panic because, oh loads of things, like I’ve got lymphedema in my arm now this is a new thing so I’m like ‘If they touch my arm are they gonna notice?’ ...And I’ve got scars all over me.” – Melanie

From her account it is clear that Melanie perceived the visible and tactile changes to her body as preventing her from being able to pass as ‘normal’, and this shaped how Melanie interacted with potential partners. I asked her to describe how being intimate with a new partner is different now.

“In terms of like having sex with somebody I’d be like ‘If we can just turn the lights off’, I will be scared about where they touch me or just like, it’s just so different it really is....Before I was much more confident with it all and now I feel like I’ve got this whole kind of like a can of worms that I need to like bit-by-bit discuss...Like ‘Oh yeah [points to body] that’s because this happened to me’ and ‘Oh yeah when you touch my arm I’ve got this’ and ‘Yeah that scar’s from this’ and, y’know, the guy’s thinking ‘I don’t want, God do I want to be with someone like this?’” – Melanie

Melanie’s description shows how she perceived herself to be less attractive to men because of all of the things that had happened to her, and her body prevented her from being able to hide her experiences, instead displaying them for partners to see. This profoundly altered how she experienced sexual relationships, and she was happier dating men who she would be able to get to know better emotionally before entering into a physical relationship.

Young women experienced a dissonance between the reality and expectations of their bodies, causing them to feel at odds with their bodies. Treatment-induced menopause was experienced as premature ageing, and other effects, such as weight gain and changes to body shape, were often attributed to treatment-induced menopause. The peculiar sensations, and changes to physicality and mobility resulting from treatment and reconstruction, were difficult to negotiate and altered their behaviour in their everyday lives. Similarly, the loss of libido was described as a strange experience, which challenged young women’s previous perceptions of their bodies. The physical effects of treatment were experienced as bodily reminders, betraying the reality of what had happened to them.

Embodied experiences of being diagnosed during pregnancy

Three women in the study were pregnant when they were diagnosed, an experience which was profoundly difficult for the young women. As discussed in the literature review, this is an under-researched phenomenon unique to young women. The accounts of the three women

in this study who were diagnosed while pregnant – Catherine, Dawn, and Lyndsey – revealed that this was a further dimension of the embodied experience of breast cancer for young women.

Lyndsey described having to undergo a painful tissue biopsy, which was made difficult because breast tissue becomes denser during pregnancy.

“They were struggling to get the biopsy needle in, so she was like putting loads of weight on me and everything like really straining to get this probe into me. And she took three biopsies, and by the second one I actually said ‘I’m really sorry you’re gonna have to stop’, because I felt really nauseous and horrible, I felt like I was gonna faint.” – Lyndsey

She described how she felt upon hearing she had cancer and would need treatment while pregnant:

“My main concern obviously was the baby because I was like crazy about it at that point, it was wriggling around all over the place and I couldn’t keep my hands off it.” – Lyndsey

She then underwent a lumpectomy under general anaesthetic, and recalled her immediate response upon waking up from the surgery.

“I had my hands on my tummy as soon as I woke up, I remember coming round from the anaesthetic...I put my hands on my tummy and almost immediately felt the baby kick so I was like ‘Thank goodness for that’.” – Lyndsey

Lyndsey's account illustrates that her breast cancer diagnosis had implications for not only her body, but also her unborn child's, and she was able to be reassured that her baby had survived through the bodily experience of feeling it move.

I asked all women about the long-term impact of treatment on their bodies, and the women who were pregnant at diagnosis felt that it was difficult to tell whether the changes which they experienced were as a result of treatment or the pregnancy.

"It's really difficult because having a baby at the same time as having the treatment, your body changes massively through having a baby." – Catherine

This illustrates that being pregnant at diagnosis increased the dissonance which the young women experienced between the expectations and realities of their bodies after breast cancer.

The data here is limited because of the small numbers of women interviewed who were pregnant during diagnosis. However, I have been able to identify important themes for wider exploration, and illustrated the impact of such an event on the embodied experience of the young women.

Conclusion

The findings in this chapter have provided evidence that women were at odds with their bodies in a number of key ways. Firstly, the young women experienced and perceived their bodies to be a source of danger, inherently risky. This was related to the nature of cancer and its apparent duplicitous ability to be hiding with the body, and the inability of medical knowledge to define them as cancer-free. It was also, importantly, related to their age at diagnosis because of the nature of hormone receptor-positive breast cancer, and the many decades ahead during which cancer could recur. Further, the sense of their bodies as risky

impacted on young women's interactions with others. These findings provide insight into young women's perspectives of CPM, as well as extending knowledge about embodied risk, developing its age-related dimensions. Risk of recurrence was not a prominent theme in all of the interviews, and exploring these accounts highlighted the significance of women's experiential knowledge, and chemotherapy, in understanding their perceptions about recurrence.

The second major finding was that young women encountered a gap between their own and others' expectations of their bodies, and the reality. This was a result of the effects of treatment-induced menopause, the impact on sensation and physicality and subsequent consequences for their everyday lives, and the effect on their sexual desire and experiences. Asking women to talk about how their bodies felt after treatment revealed important insights into the impact on sensation, but also the ways that sensation and appearance were interwoven in women's lives. A number of the ongoing effects of treatment were experienced by the women as premature ageing, and bodily reminders, and revealing what had happened to them in situations in which the women wished to forget.

Finally, this chapter explored the accounts of the three women who were diagnosed during pregnancy. This analysis illustrated that the diagnosis held implications not only for the young women's bodies, but also of their child's. It also showed that it was difficult for the women to distinguish whether the changes to their bodies were as a result of treatment, or the pregnancy. Although there is a limited amount of data due to the small numbers, the accounts demonstrate the profoundly distressing impact of this under-researched experience.

The next chapter addresses the question of the extent to which biographical disruption characterised the young women's experiences and perceptions.

Chapter Seven – The significance of biographical disruption in young women's accounts of living with a history of breast cancer

Introduction

In this chapter, I draw on the young women's accounts to explore the extent to which biographical disruption characterised their experiences and perceptions. The literature review demonstrated that biographical disruption (Bury 1982) has been identified in studies exploring the experience of cancer, but has not been considered in studies about the lives of young women after breast cancer. It also suggested that the concept of cancer survivorship may be a resource which young women draw on in the face of the disruption caused by breast cancer. The concept of liminality (Little *et al.* 1998) was also introduced, and the analysis of the literature suggested that it may characterise the experiences of young women after breast cancer.

The chapter first considers the onset of symptoms and the diagnosis, exploring the biographical disruption which many of the young women experienced, and the features of this which were associated with their age. This includes the particular experiences of three women diagnosed during pregnancy. I then discuss the women's experiences and perceptions of uncertainty, which emerged as a significant theme in their accounts of their lives following initial treatment. Two broad dimensions of uncertainty were experienced: uncertainty related to recurrence and survival, and uncertainty regarding fertility and menopausal status. I present these two dimensions respectively, considering how such uncertainty can be conceptualised as a liminal state (Turner 1979; Little *et al.* 1998).

Following this, I explore two further major disruptive effects on young women's lives, and

the ways that these were related to the young women's age at diagnosis, namely: a loss of agency over the life course; and the impact on personal relationships.

Onset of symptoms and diagnosis: biographical disruption

Women under 47 are not currently included in the NHS annual breast screening programme, and, therefore, the majority of women diagnosed under this age are symptomatic. Prompting women to begin their story from when they first thought something might be wrong revealed that the process of discovering symptoms and seeking advice from a GP, involved “attention to bodily states not usually brought into consciousness” (Bury 1982:169), and contradicted their taken-for-granted ideas about themselves as young, healthy women. Many of the young women described initially rationalising their symptoms as being related to their menstrual cycle, or as blocked milk ducts or benign cysts, because they did not think they could get breast cancer at their age.

“You’re 35; you think it’s just a cyst.” – Philippa

“I didn’t think it was ever gonna be me I thought ‘Oh I’m too young’.” – Lyndsey

Decisions about seeking help were identified by Bury (1982) as a major element in the initial stage of biographical disruption. For a number of the young women, visiting their GP about breast cancer symptoms involved a process of contradicting their own and others', assumptions about what is possible or 'normal' at their age, and they had to re-assess their ideas about what was possible within their own biography.

The majority of the women were referred immediately by their GPs, but four women reported having to return on multiple occasions before eventually being referred to a breast clinic. The interviewees reported that these experiences with their GPs occurred because of their age.

“It didn’t go away so I went back another time...They treated me a bit like I was being a bit silly. And they even went ‘Do you want me to check you again’? And I was like ‘Yeah it’s still there’, and they said the same thing: ‘It’s probably nothing’...So I’m 26 and I’m thinking, you think doctors know what they’re talking about.” – Naomi

“[GP] said was it a bite mark and thought that was quite amusing and then asked me if I was actually drunk at the time, which was quite y’know it was quite insulting, and I kind of just wanted to leave...I thought ‘Well obviously the doctors know what they’re doing so y’know they’re the professionals’.” – Gemma

“I saw my doctor three times between finding it and actually being diagnosed, that took about twelve months...The second time I went to see him I said the skin had started to dimple...It had always been at the back of my mind thinking ‘That’s not right, I’m sure that’s not right’. And at which point he told me: ‘You’ve put a bit of weight on recently and it’s probably something to do with that’...I went away thinking ‘Well the guy’s a doctor he knows what he’s talking about’.” – Philippa

Early diagnosis is known to be significant in leading to better prognosis (Love 2010). This means that a delayed diagnosis as a result of the ageism reported by the women above could have been dangerous and led to a poorer outcome. Throughout diagnosis and treatment, the women found that their sense of being too young to have breast cancer was reinforced by health professionals.

*“Every time you went to a new department for a different kind of scan or saw a different nurse for like a blood test, they were like ‘Oh you’re **so** young!’ Like **every** time. The amount of times I got that it was like: ‘I know how old I am!’ [Laughs] It*

was like you were some alien because you were so young.” – Faith [participant’s emphasis]

“My consultant was totally surprised...I actually remember when I was lying on the table and the mammogram came through to his computer and I heard him say out loud ‘There’s more?!’...I just didn’t fit the mould of what would be expected, like I was young, no breast cancer history in my family, like I’d just had a baby.” – Hayley

The women held perceptions about who was normally diagnosed with and treated for breast cancer, and hospital waiting rooms were identified as a particular space in which the women felt out of place.

“It does feel as though it’s an older woman’s condition...They are all silver-haired Goddesses sitting in that waiting room...People think you’re there for someone else.” – Philippa

“Waiting for the appointment to have radiotherapy where I was just surrounded by women that were the very youngest fifty plus. And that was the kind of time when ‘Wow this is just weird’...If a young person came in it was like [Gasps] ‘Oh they’ve just come to see their Nan’ or something.” – Joanna

Bury found that his participants struggled when diagnosed with rheumatoid arthritis at a young age because “their experience contrasted sharply with the common cultural paradigm of the disease” (1982:171), and this is reflected in the young women’s accounts above.

However, Vanisha, who had been receiving annual screening for ten years prior to her diagnosis, did not feel this sense of disbelief when she was diagnosed. Her breast cancer was not symptomatic, but was found through mammography, unlike all of the other participants.

“People talk about being shocked, I wasn’t...For many years I’ve thought I’d get breast cancer, knowing that my mother had died of it so young.”- Vanisha

Vanisha’s account suggests that the existing knowledge of her family history meant that breast cancer made sense in the context of her own biography, and was perhaps protective against the disruption which other women experienced. However, Vanisha later said that, although she felt prepared for the diagnosis, she was not prepared for the experience of treatment, or for the feelings of uncertainty which followed the end of treatment.

Catherine, Dawn, and Lyndsey, who were pregnant when they were diagnosed, all experienced the same sense of discomfit at the onset of symptoms and diagnosis illustrated above. However, they felt even more different to other women with breast cancer.

“There were lots of people at the reception in the hospital, I hadn’t even checked-in to say I’d arrived and the consultant surgeon spotted me in the queue and he came up, I was obviously a bit different to everyone else being pregnant as well.” –

Lyndsey

The three women also found the diagnosis to disturb their expectations of and plans about pregnancy.

“It was like someone had just said: ‘Did you know you’re having a baby tomorrow?’” – Catherine

The perceptions held by the three women, were that it felt unfair to have been diagnosed during pregnancy, and to have that part of their lives spoiled.

“It was probably what should have been one of the happiest times of my life but it is tainted with one of the worst things you could ever be told.” – Lyndsey

The women’s experiences soon after birth and as new mothers were shaped by the need to begin treatment. They were all unable to breastfeed once chemotherapy began, and this interrupted their expectations about early motherhood. Catherine described this as one of the most difficult aspects of the experience.

“That was one of probably the biggest kind of emotional things...I do feel a bit bitter about the fact that this thing is making me stop breastfeeding because it’s like um, you know it’s the best thing to do, but also it’s the closeness of that...I did feel quite sad about that.” – Catherine

Not only did the women mourn the loss of the breastfeeding experience and feel distressed about having the choice taken away from them, but they also found that it increased their sense of being different to their peers.

“Everybody else, y’know, at the NCT [National Childbirth Trust] group continues to breastfeed for six months or even longer than that.” – Catherine

The NCT group which Catherine referred to was a group of couples who were from a similar locale and at a similar stage of pregnancy. The group met throughout the pregnancy and the women continued to meet up weekly after the birth of their children. Catherine described her life during radiotherapy treatment, when she had to attend treatment every day for several weeks.

“I’d drag myself down there every day...I couldn’t do a lot of things because I felt like I had to get back in time for that...I felt at that point very different from the rest of the [NCT] group because none of them had to deal with that.” – Catherine

Treatment, therefore, interfered with Catherine’s everyday life as a new mother, and she found herself feeling profoundly different to her peers.

For Dawn, the likelihood that treatment would affect her fertility had made her feel during treatment that, despite the side-effects of chemotherapy, she wanted to do as much of the caregiving as possible.

“It was likely that I wouldn’t be able to have more children afterwards so I kind of still wanted to do that, do most of the things for yourself really.” – Dawn

Lyndsey felt glad that her cancer was hormone receptor-negative because she felt that this made future pregnancies less dangerous than if it had been hormonally associated. In contrast, Catherine, who had conceived her child through IVF, considered the possibility that the IVF treatment or pregnancy had actually caused her breast cancer:

“Maybe having children and being pregnant was never meant to happen to my body.” – Catherine

Missing from this and other research, are the voices of women who have had to terminate a pregnancy in order to commence life-saving breast cancer treatment, some of whom will then be unable to have more children as a result of the treatment. Catherine, Dawn, and Lyndsey were all aware of these women’s experiences.

“We found the lump early enough that we didn’t have to make any horrible decisions about this much-wanted baby.” – Catherine

Being diagnosed during pregnancy made each woman feel that her child was all the more precious, and all three women expressed feeling immensely glad that they were able to continue safely with their pregnancies.

Thus far in this chapter, I have shown that biographical disruption characterised many of the young women’s experiences from the onset of symptoms and throughout diagnosis of and treatment for breast cancer. I now go on to discuss the young women’s experiences and perceptions of uncertainty following the end of initial treatment.

Uncertainty accompanying the end of initial treatment

Uncertainty emerged as a significant theme in the women’s accounts of their lives after treatment. The young women faced uncertainty about two areas: the possibility of recurrence and their status as survivors; and fertility and the future of their life course. The young women’s lives, and assumptions about their lives, had been challenged during the diagnosis and initial treatment stage, as I have illustrated, but the implications for the rest of their lives were as yet uncertain, and this was something which the women described as having to face from the end of initial treatment. In this section I discuss the uncertainty which they described, conceptualising it as a liminal state (Little *et al.* 1998). As discussed in the literature review, liminality refers to the sense of being located between two identities or states. Uncertainty has been found to be a significant aspect of the experience of breast cancer (Crouch and McKenzie 2000; Halliday and Boughton 2011). The findings in this chapter delineate the age-related dimensions of uncertainty in this experience which has not been previously explored, and I also draw on the theoretical framework of liminality to understand the young women’s experiences.

Uncertainty about recurrence

The young women experienced profound uncertainty surrounding the question of whether their treatment had been successful, and whether they would experience a cancer recurrence. In many of the interviews, women described treatment in such terms as a ‘rollercoaster’ or ‘whirlwind’, and they contrasted this sharply with the end of initial treatment which was the point at which ‘everything stopped’. Support from others also began to ebb away at this point, including health professionals.

“The treatment it’s like at breakneck speed...And then afterwards it just stops...I started to take anti-depressants...The cold light of day y’know it dawns on you and the percentages start to kick in and ‘Oh shit y’know that’s not good’.” – Ruth

“You get so much support from friends and family...It all dies down naturally, and so you just kind of feel a little bit alone then.” – Lyndsey

The treatment ended, it seemed, abruptly, and women had expected to feel positive and well, especially at the end of chemotherapy. Instead, they found that they felt emotionally and existentially vulnerable, reflecting on the enormity of the experience of having gone through cancer treatment and its implications for their future. The fear of recurrence has been noted in other studies about the experience of breast cancer from the perspectives of women of all ages (e.g. Dunn and Steginga 2000; Allen *et al.* 2009; Adams *et al.* 2011).

The young women in this study felt that it was particularly difficult for them to face their mortality and the possibility of a foreshortened life span at their age. They considered the possibility of recurrence and its implications for them as younger women, and having to live for such a long time with the burden of this uncertainty.

“There’s something about realising your own mortality at quite a young age, um in a way that most of your contemporaries aren’t thinking about in their 40s or 30s y’know. Most people don’t reach that until a couple of decades later or when their parents die or something like that, but you’re forced to confront it at a much younger age really.” – Vanisha

“The younger it happens to you, you think that it’s more likely to if it does reoccur, because your chances are quite high, that it’s gonna reoccur while I’m still young...If you get cancer when you’re 60 and you look at it that you may get it in ten years’ time you’re at a fairly good age, whereas if I get it back when I’m 40, which might not happen but there’s still a huge chance that it will, I’m still like super young really at 40.” – Lyndsey

Lyndsey had witnessed her Aunt’s death from a breast cancer recurrence ten years after the initial diagnosis. As a result of this, she felt convinced that the same thing would happen to her at 40.

“I’m 30 so I keep thinking when I’m 40 it’s gonna be me, and you just can’t help thinking like that. And it will just taint my whole future, I know that I’ll never be able to stop thinking about it, worrying about it.” – Lyndsey

This echoes findings from Hesse-Biber’s (2014) study about women with a BRCA gene mutation. She found that women who had a family history of breast or ovarian cancer perceived a ‘cancer clock’ (p.89), or a timeline when they thought there were likely to get cancer, based on the age at which their relatives had been diagnosed.

The young women found their assumptions about their lives into old age challenged by the possibility of recurrence and they had to incorporate this into their biography.

“The plans that I had with [partner]...In terms of when the children are older she’ll live with me, we’ll live together, y’know all these things, um, I realised that they might not happen.” – Vanisha

“I think most of my family kind of go a bit doolally, but I used to kind of worry about being old and crazy kind of thing, whereas now I do kind of think ‘Well maybe I just won’t get old at all’.” – Ailsa

The young women also talked about having to make plans for their children’s and partner’s futures in case they experienced a recurrence and passed away.

*“One of the things I’ve made sure I’ve done while I’ve been off is make a will...Both [husband] and I now have had life threatening conditions and we have a seven-year-old daughter, and there’s still loads of growing up for her to do yet, and I worry a **lot** about whether we’re gonna be around. So I’ve had conversations with my brother about taking over her care should the need arise.” – Charlotte*
[Participant’s emphasis]

“If it comes back and if it comes back at a stage where there’s no cure or whatever, what’s gonna happen with my family? Um, so it’s thinking about things like that, putting plans in place that...When you’re doing things you do things just in case this happens let me make sure I’ve done this.” – Sarah

Sarah and her family had moved house since her treatment, and she described how, during house-hunting, she had been thinking about how her husband might use the house in a future without her.

“Because of [husband’s] age he’s bound to meet a woman – with kids possibly – and he’s gonna have to accommodate as a family a house big enough for that family. So even when I was looking at the property to buy I was even thinking ‘If I went and [husband] had a new family could this family house in this house?’” – Sarah

In their exploration of the experience of liminality after cancer, Little *et al.* (1998:1485) identified a theme in their participants’ accounts which they termed ‘boundedness’. This was characterised by a sharpened perception of “existential constraint, an awareness of the uncertainty of future time” (p.1488). Awareness of one’s mortality and uncertainty about the future were present throughout my participants’ accounts, profoundly affecting their perceptions of their own and their family’s future.

Uncertainty about being cancer-free

In Chapter Six, I argued that the young women experienced embodied risk, and perceived cancer to be lurking within their bodies. This uncertainty about whether the treatment had truly worked, and if they were cancer-free, shaped the young women’s self-perceptions. Rather than being categorised as either ill or well, the young women found themselves in a space ‘betwixt and between’ healthy and ill (Turner 1979:94). This was reflected in the young women’s negative opinions of the label: ‘breast cancer survivor’. I initially asked the question “do you use the term ‘breast cancer survivor’ about yourself?” to consider if and how young women drew on it when performing the work of reconstructing or maintaining their identities after breast cancer, but it soon became clear that, for almost all of the women, this was not something which they could draw on positively.

“If I say ‘I’ve survived’ maybe the bugger will come back and bite me on the backside...And say ‘Ah you’ve not bloody survived have you!’.” – Ruth

“Technically yeah [I am a survivor] but I daren’t say that in case it comes back. It feels like it’s tempting fate y’know?” – Philippa

“If I call myself a breast cancer survivor, then when I get a reoccurrence I’m no longer a survivor am I? [Laughs] Y’know how does that change that then? Um, yes I’ve survived this first um primary breast cancer tumour, but I don’t think it’s as simplistic as I’ve survived full-stop.” – Vanisha

The quotes above illustrate that the women were living with the uncertainty of their status as having ‘survived’ as a constant presence, and this made it difficult to identify as survivors. Two British studies have reported similar findings (Khan *et al.* 2012b; Trusson 2013), as discussed in Chapter Three. A quantitative study with 240 US women, also reviewed in Chapter Three, found that younger women were more likely to consider themselves to be survivors (Helgeson 2011). The current study is not statistically representative, but it does not support this suggestion. Three of the twenty women did say that they identified as survivors to some extent, but the concept of survivorship did not characterise the experiences of the majority of the young women interviewed. Instead, the lines between ill and well were blurred, or as Sontag phrased it, they belonged neither to the “kingdom of the well [nor to the] kingdom of the sick” (1990:3). Their awareness of their mortality, and the possibility of recurrence, was ever-present. This adds support to the literature on liminality after cancer, which has identified liminality in individuals with different types of cancer (Navon and Morag 2004; Cayless *et al.* 2009; Hubbard and Forbat 2012), or older women with breast cancer (Trusson 2013). It also adds further nuance to the theory of biographical disruption, making uncertainty a central concept for understanding the experiences and perceptions of young women living beyond initial breast cancer treatment. The following sections explore further aspects of uncertainty which were related to the women’s age and life stage at diagnosis.

Uncertainty about fertility and menopausal status

A further dimension of uncertainty which the young women experienced was surrounding fertility and menopausal status, and this was a significant theme in many of the interviews. The accounts indicated that, regardless of future family plans, the uncertain menopausal state which treatment induced for many of the young women was experienced a liminal state because of the inability of health professionals to define their menopause as permanent or temporary. This dimension of uncertainty is central to understanding young women's experiences after breast cancer. While previous research (Trusson 2013) has identified liminality in the accounts of women with a history of breast cancer, this dimension is related to the young's women's life stage at diagnosis, and it therefore extends understanding of life after breast cancer. I will first discuss uncertainty around fertility in the young women's accounts, before exploring uncertainty about menopausal status.

The impact of breast cancer treatment on an individual young woman's fertility is difficult for health professionals to determine (Camp-Sorrell 2009). This was a major issue for the young women and was discussed at length in many of the interviews. Reproduction and fertility have been identified in previous studies as among the most important concerns of younger women living with a history of breast cancer (e.g. Dunn and Steginga 2000; Thewes *et al.* 2004; Adams *et al.* 2011), but here I highlight the importance of the *uncertainty* about fertility and the way that this can be understood as a liminal state for the young women.

"I'm aware of how much the fertility dominates [the interview]...This could mean I couldn't have children and that's something that's been a dream forever so that was the biggest [issue]." – Joanna

Thirteen of the participants told me that at the time of their diagnoses they had been planning on having (more) children, or were undecided but had not ruled it out. Many of the

women interviewed were therefore hoping that the menopausal symptoms they were experiencing were temporary, and that their menstrual cycle would return to normal once they finished long-term treatment, and that they would be able to conceive.

“No doubt I’ll find out in the next few years whether I can [have children] or not, assuming I’m in the position to start.” – Faith

Even those women who were no longer receiving long-term hormonal treatment, and had been told by their doctors that their fertility was normal were still experiencing profound uncertainty.

“I have no doubt it’s affected my fertility. I mean I’m back now, I’m totally regular I have periods even after my second chemo, and I asked my oncologist to give me a fertility test and he’s like ‘Yep you’re fertile’. But I know I will never know until I, fingers crossed, try to have children.” – Melanie

For Naomi, becoming pregnant was a major goal and would be the point at which she would feel recovered from the cancer, and her liminal state would end.

“We’ve got two years left of Tamoxifen....And then we’ll start trying for a baby. Which is the ultimate goal now, after, and that will be my ‘That’s it, put it behind me’. That’s always been like my end to it all. So I’ll be living it now until that moment where I can say I’m pregnant. And then I’m gonna put it behind me as much as I can.” – Naomi

The uncertainty which arose with regards to fertility can be understood as a liminal state in which the women were unable to categorise themselves as either fertile or not, able to have

children or not, and many of the young women were waiting to not only move on to the next phase of their lives, but waiting to see what would be possible within the next phase.

“You feel like you want to, not wish your time away, but you want to like get through the next month and keep counting down.” – Joanna

All but four of the women were still on long-term hormonal treatment, such as Tamoxifen, which inhibits the amount of oestrogen absorbed by cells in the body in order to prevent recurrence. The length of this preventative treatment, and therefore the length of their treatment-induced menopause, was largely uncertain for the young women.

“[It would] just be nice if they say after five years: ‘That’s it we can stop it’.” – Gemma

Some of the participants were told when they began treatment that they would be able to come off Tamoxifen after two or three years in order to have a child and then go back on it to complete the five-year recommended course. However, this was something which the women were unsure would actually happen.

“After three years of taking it, if it’s all clear and we’re happy, we could think about coming off it to try and have children... We just have to see how it goes.” – Evelyn

“My oncologist wants me to be on hormone treatment for at least two years, I need to be on it for minimum five in total but he has said that after two years I can maybe have a break to have a child.” – Hayley

It seemed that, for some women, if they did not experience a recurrence within the first two or three years they might be able to take a break from their hormonal treatment in order to

have children. Uncertainty about recurrence and fertility were, therefore, interlinked. A few of the women had tried to negotiate taking this break from their Tamoxifen regime in order to conceive. However, this was less straightforward than they had hoped, and they had found their doctors resistant to the idea.

“I went in and I said ‘I want to finish’ and he said ‘No’. I said ‘I’d like to start having kids’ and...He looked at me and said ‘Naomi if you stop your Tamoxifen now and have a baby you won’t be here to look after it’.” – Naomi

The young women had to balance their wishes to have children, with the importance of preventing recurrence. This highlights important distinctive aspects of young women’s experiences of living with a history of breast cancer: that of uncertainty regarding fertility; the length of time of such uncertainty; and the implications of breast cancer on their life course. Waiting until the end of long-term treatment, or until their oncologists agreed that they could take a break, to find out if they could conceive, was experienced as a liminal state. Uncertainties about recurrence and fertility therefore interweaved to produce an uncertain future for the young women.

Not all of the young women were hoping to become mothers, and some of them had already had all the children they were planning to. Seven of the women were not, at the point of diagnosis, planning on having any (more) children. Another two women told me that they were not planning on having children after their treatment because of their experience of cancer. It is important not to neglect these women’s accounts, or to imply that all young women wish to have children. However, concerns about menopause and fertility did not necessarily relate to a desire for children, and an uncertain hormonal status had an impact on women’s identities regardless of whether they wanted children. None of the women interviewed had experienced menopausal symptoms before their treatment. A few of the

women described welcoming the end of menstruation, a finding also reported in Perz *et al.*'s (2014) study.

"I never planned to have children; I never wanted children, so I was quite happy to get rid of the periods." – Vanisha

"Going down the tampon aisle, I've got to be honest, I don't stand there and think 'Oh I long to use you again'." – Philippa

For the women who were not planning on having children after treatment ended, uncertainty still characterised their experiences because they were unsure if they would return to a pre-menopausal state after treatment.

"Once the injections are finished they don't know whether my periods will restart, they can't tell me that." – Beverley

Some of the women were hoping their periods would resume and their menopausal symptoms would subside until they became naturally menopausal later in life. Others were hoping that the treatment-induced menopause was permanent. The perceived risk associated with a return to pre-menopausal hormonal status was discussed in Chapter Six, and this was the reason some women were hoping their menopause was permanent. Others had different reasons which reflected the burden of uncertainty in the women's everyday lives.

"They're testing me at the moment just to see if I've actually gone into full menopause, um which I don't mind if I have, but it would answer a lot of questions about the forgetfulness, the weight gain, the hair loss, it would answer a lot of that. I would stop worrying about it so much 'Oh is it the drugs and if I stop taking them will all these things suddenly come back with a vengeance?'." – Sarah

This builds on previous work on liminality, demonstrating that there were particular ways that liminality was connected to their age at diagnosis.

In the sections that follow, I will explore further major disruptive aspects which the women described, exploring how biographical disruption and liminality had implications for different areas of life for the young women interviewed. The aspects explored are: the loss of control over their life course and the effect on personal relationships.

Young women's loss of control over their life course

A further dimension of biographical disruption and liminality was that of a loss of the previously taken-for-granted control over the life course, especially in relation to choices about when to have children. In this section I argue that, while the young women identified some positive ways in which they were able to regain some agency, they experienced a loss of control over their lives. Some women spoke about accepting this outcome of breast cancer, but many felt ambivalent about it, and this highlighted the sense of powerless over their lives which the women experienced and perceived.

Gaining control and confidence through helping others

Despite the disorder and uncertainty which breast cancer caused, a number of the women reported positive effects of their experience with breast cancer, often without prompting.

One positive aspect identified by a number of the women was the ability to help other women in similar circumstances, and being able to empathise with others. They found that their confidence had increased and they were now able to speak in front of groups of people about their experiences.

“I’ve gone along [to the breast care centre] and I’ve spoken a little about my situation, and about yeah the group we run. And I don’t think I would ever have really had the confidence to do something like that before.” – Dawn

“Yeah I can’t really explain it, ‘cause if you’d said to me a few years ago I’d be speaking to school children and college kids about breast cancer I’d be like ‘No way!’ No I hate giving presentations at work and stuff like that, but yeah, I don’t know. It seems like the right thing to do.” – Faith

“But confidence-wise, I’d never like get up in front of a room full of people and speak, but I bloody would now. I think it’s ‘cause I think, ‘Well y’know what’s the worst that can happen? It’s not gonna kill me’.” – Ruth

Quite a number of the women felt that being able to help others by sharing their experiences was a very valuable exercise. Little *et al.* (1998) argued that such activities can alleviate the sense of a loss of agency and empowerment after cancer treatment. The young women in this study perceived this as a positive outcome of their experience.

“I think ‘Why did I go through it all if I’m not gonna do anything about it?’ ...It’s such a negative experience you want to just forget it, but try and turn it into something positive.” – Melanie

As Melanie’s account illustrates, being involved in a charity or support group was seen by some women as a way of giving meaning to the experience, and transforming a negative experience into something positive.

Accepting a loss of control

Some of the women expressed a sense that they simply had to accept the loss of control over their lives, with some indicating that this made them less anxious about making sure their lives took the ideal course they had anticipated.

“I don’t mind because it’s part of my story, I like that I have a story, rather than...A lot of my friends have gone through the whole like college, uni, work for a bit, get married, have a baby: the whole like ‘life plan’. And I kind of like that my life’s been shaken up a bit now. Although that’s what I wanted, I’ll get that eventually. I’ve got a really good boyfriend I know that that’s the way life’s gonna go for us.” – Naomi

“We try not to plan too much because we just don’t know...I think our main thing is just staying strong and staying healthy....Just try and be positive and upbeat. And not make too many plans because we did that before and then I was ill so. And that changes everything so you can’t, you can’t over-plan.” – Tabitha

These accounts illustrate how the young women found that accepting that they could not control their lives was a way of coping with the interference with their life course. However, the following quotes from the same two women highlight that these accounts were set in a context of a perceived sense of powerlessness.

“You kind of have to accept it don’t you? If I don’t accept it I’ll just get angry every time I see my friend with a baby. It does really wind me up that I can’t do what my friends are doing.” – Naomi

“It just makes you think ‘Okay well right, do what you want to do and just enjoy it’. I think that’s all you can do really.” – Tabitha

Constraints of treatment timescale

The treatment for breast cancer for a young woman who receives Tamoxifen, can take over six years including surgery, chemotherapy, and radiotherapy. Further breast surgeries, such as reconstruction, can extend this even further. This had particular implications for the some of the young women who were at a certain stage in their life, as it meant that the following six years from diagnosis would be dramatically different to the way the women had planned or anticipated them to be, displacing their major life plans.

“I just can’t wait until it’s over, I just can’t wait. It’s like a pause on my life.” –

Naomi

The uncertainty which accompanied this disruption was significant in the young women’s accounts. Not only were their ideas about the future challenged, but, for the women who were receiving Tamoxifen, they were constrained by the timescales set by their treatment. The end of hormonal treatment does not immediately signify the point at which women might be able to conceive; the drug takes time to leave a woman’s system, and women are advised not to try to become pregnant for twelve weeks (Hickey *et al.* 2009).

Because my Mum had an early menopause at 40, 41, and I knew...I would have to have Tamoxifen for five years and that I wasn’t allowed to get pregnant in that space of time...I knew then that I’d be 38, 39 coming out of it and that I’d have only a tiny little window, potentially a tiny window to get pregnant.” – Evelyn

Evelyn’s account illustrates the importance of timing, and the burden of the implications of this uncertainty on the young women’s lives. For Evelyn, the years on Tamoxifen stretched out ahead of her, and the time between the end of treatment and her anticipated early menopause was too short, restricting her chances of having children.

Like participants in Kirkman *et al.*'s (2014) study, the women often held perceptions about the ideal time to have children, and breast cancer treatment left this temporal trajectory in disarray.

"I was kind of hoping that I'd have a child by at least 35, one, um, and we want to have a couple, so at least by the time I was 40 I was thinking we'd have two children. Um, and that's just not gonna happen now." – Evelyn

Being in a relatively new relationship at the time of diagnosis, Naomi had feared the impact on having to make such important decisions.

*"I was more scared that my boyfriend was gonna freak out because it's quite a lot to take on for a boy after a year of a relationship, like suddenly my girlfriend's got cancer and suddenly we're being forced into the decision of being like we've got to **freeze babies**."* – Naomi [Participant's emphasis]

Diagnosed at the age of 26, Naomi expressed her sense of injustice at, and frustration with, this loss of control. She described how she felt when her oncologist refused her request to take a break to have children:

"I felt like a 60-year-old man [consultant] is controlling my life." – Naomi

Many of the young women felt that they were deviating from a 'normal' life course, as well as their personal anticipated life trajectory, often comparing themselves to other women their age.

“A lot of my friends have got a child around [son]’s age, and I see 90% of them now have a second child, um, and I can’t even think about having, even starting to try for another year.” – Hayley

“All my friends and everyone around me is on one path and I’m kind of going, poodling on another.” – Naomi

Naomi’s use of ‘poodling’ indicates that she viewed the time on Tamoxifen to some extent to be wasted time, illustrating her experience and perception of a liminal state. Melanie described the sense of urgency which she felt to meet a partner and complete certain goals before she experienced a recurrence:

“Yeah deep down I think to myself ‘God I need to meet someone quickly and have them fall in love with me’ because God forbid it comes back.” – Melanie

Existing research has noted that women with breast cancer experience a loss of control over their bodies and lives (Dunn and Steginga 2000; Thomas-MacLean 2004; Burles 2010; Trusson 2013). Halliday *et al.* (2014) also found that loss of control was a strong theme in their study about the experiences of women who were uncertain about their fertility after haematological cancer treatment. The findings in this chapter highlight that young women with breast cancer experienced a loss of control which was related to their age at diagnosis and the implications of treatment for their life course.

There is a concept emerging in research and writing about cancer experience, that of the ‘new normal’ (Mukherjee 2011a, 2011b; Denford *et al.* 2011; Sherman *et al.* 2012; Trusson 2013). In the oncologist Mukherjee’s (2011a:449) book, a woman undergoing treatment states that, “for someone who is sick, this *is* their new normal” (original emphasis). She was referring to her everyday life which had become structured by treatment. In a newspaper

article about his book, Mukherjee argued that, for someone living beyond treatment, living in the shadow of cancer becomes their ‘new normal’ (2011b:27). Trusson (2013) approached her research with the question ‘what does the new normal look like for women living beyond breast cancer treatment?’, thus assuming that there is a new normal. It could be argued that some women may find it useful to frame their lives living with the uncertainty engendered by cancer as ‘normality’, and indeed one woman in my study used the term ‘new normal’:

“It’s normal for me to wake up feeling about 80, like if I got up now I would probably hobble for a little bit but be fine and it’s just a new normal for me. So I don’t sit there thinking ‘Oh God I’m like this because I’ve had breast cancer’, I just think ‘It’s what I need to do to survive’. It’s like a survival tactic or, I don’t know, I have to do it so I can be here.” – Beverley

However, I think the accounts of the young women in this study raise a question about how relevant this concept is to understanding their experiences and perceptions. While the young women sometimes spoke about having to accept the changes to their life course, this was experienced in the context of the experience and perception of powerlessness. Beverley’s account above indicates that she feels that she must accept the changes to her life in order to survive. Further, the uncertainties which arose from their experience of cancer, and the constraints placed on their lives as a result of the treatment, suggest that the women were in a state of liminality, waiting to find out what the implications for their lives would be, and if cancer would return before they were able to reach their life goals.

“At work sometimes I do walk along my corridor if I’ve had a good day and I just think ‘This is great I’m okay’, and I do have that fear, I definitely do, that I need to hurry up with things, I want to sort out my life like just in case I get ill again.” – Melanie

While Trusson (2013) conceptualised this liminal state as the new normal, it could be argued that labelling it normality obscures young women's perception of their current state as temporary. The ambivalence which women expressed in their interviews illustrated that, while there were positive outcomes of breast cancer and their lives had, in many ways, resumed previous routines and structure, uncertainty and liminality permeated their everyday lives, and the sense that their current state was only temporary was ever-present.

Effects on personal relationships

In this section, I explore the effects of breast cancer on women's personal relationships, illustrating particular effects which were related to their life stage at diagnosis. I illustrate that, while the women often described feeling closer to their partners who had supported them through treatment, they also described a sense of difference to, and distance from, people around them. This was, in large part, because of others' expectations of survivorship, which were in conflict with the reality of the women's emotions. This sense of alienation may be experienced by women of all ages with breast cancer, but it was exacerbated by the fact that many women found it difficult to access experiential support because they felt that mainstream support groups did not cater to their age-specific needs and concerns.

Impact on relationships

A number of the young women described breast cancer as having a positive effect on their emotional intimacy with their partners when they had been supportive.

"It's brought us closer together because when you're going through something as, um, as difficult as that, you have to be open and honest and truthful I think, and you have to say what's worrying you...I feel like, not that we weren't together before, but we genuinely are a team, we are a unit." – Tabitha

“I don’t think I’d ever imagined that that’s what it’s like to have somebody just standing by you through stuff, it’s amazing it’s really, really amazing.” – Olivia

The young women also valued friendships which were maintained throughout their experience of cancer. However, they also spoke about negative effects on friendships, which they perceived to be because some people were unable to cope being around someone who had breast cancer.

“You do lose friends...They didn’t know how to support me through it. So instead of doing something, they’d do nothing. So then you’d lose contact with them.” – Kim

“I’ve found out who my friends are. I think that’s something that happens to you because people you thought would be supportive just disappeared...It’s the same way as in a bereavement, people shy away because they don’t know what to say to people...But then, y’know, the people that you thought wouldn’t be there are there.”

– Ruth

They were also sometimes able to forge new friendships with other young women who had been diagnosed with breast cancer, through their charitable work.

A number of the young women spoke about a changed relationship with their parents, and this was related to the fact that they felt that it was unexpected that they would be diagnosed with cancer at such a young age. Breaking the news of the diagnosis to parents was described as particularly difficult as a daughter.

“You kind of get this sense of guilt having to tell people...Especially when it’s your Mum, especially when it’s something that in our society it’s mainly thought of

women her age in their fifties that should be going through this, not their daughters in their twenties.” – Naomi

When Tabitha told her family, they had all gathered at her parents’ home to hear the news, expecting that she and her husband were going to announce that Tabitha was pregnant.

“I think that’s probably the day that I hurt my parents the most...I felt like I’d broken their hearts that day ‘cause they were just beside themselves really...To have this happen now and be so young and still sort of newly-wed-ish phase and all of that, thinking I’m pregnant.” – Tabitha

Social expectations about who normally has breast cancer, and the life goals which women should have been reaching at their age, therefore, informed their relationships with their parents following diagnosis.

“My parents, they’re not young anymore...I want to be worrying about them, and I feel all the time my Mum is – I think she doesn’t sleep at night worrying about me.”
– Melanie

Breast cancer, therefore, had negative effects on some of the young women’s personal relationships, and this was in part due to the biographical disruption which the young women experienced, and the ongoing uncertainty about recurrence and health status.

Expectations about survivorship

Earlier in this chapter, I illustrated that the majority of the young women interviewed did not identify as survivors, finding that their uncertainties about recurrence in particular were a barrier. One outcome of this was that the young women found that their own and others’

expectations about cancer survivorship contrasted sharply with the reality of their experiences and perceptions of life after initial treatment.

“I hide it massively, like I can put on such a good front so easily...I can hear people, well like my parents’ friends especially being like ‘Oh she’s just so inspirational’ ...But they don’t know the rest of the crap I don’t tell people when I go for a scan or when something bad’s happened.” – Melanie

“You don’t want to keep whingeing about it and I don’t, you don’t want to keep bringing it up and it’s like ‘Yeah get over it Lyndsey’ [Laughs] ‘You’re like a year on now shut up’...They wouldn’t say it but I think maybe they think it.” – Lyndsey

For the young women, not only were they experiencing profound disruption to their lives and suffering with deep uncertainties, but they felt unable to communicate these to some key others because of others’ expectations about cancer survivorship.

“People expect you to be back to normal...You kind of want to shake people and go ‘I’m not okay, just listen to me!’” – Gemma

Their apparent return to ‘normal’ meant that emotions perceived to be negative, such as worry, were not expected, and the women thus felt restricted in the emotions which they could express. The social role of the survivor, therefore, was perceived by the women to preclude the expression of such feelings as pain, grief, or anxiety about the future, to friends and others.

Little *et al.* (1998) identified ‘communicative alienation’ in the accounts of their participants, defining it as the recognition that other people could never fully understand the experience unless they had been through it themselves. They conceptualised this as a

dimension of liminality, however, it could be understood as a *consequence* of a combination of liminality and the social expectations of survivorship. The young women in this study felt neither ill nor well, but they were not able to express this sense of an in-between state to many others around them, in part because others had not been through the same experience, but also because they perceived the survivor role to foreclose the possibility of divulging such feelings.

Age-related barriers to experiential support

Experiential support – the support of peers who have been through a similar experience – has been identified as very important to young women with breast cancer (Snyder and Pearse 2010). The previous section discussing the sense of difference and separateness which young women felt from their peers highlighted the importance of accessing such experiential support. At least five of the interviewees attended Breast Cancer Care's Younger Women's Forum, which is an event, held over a weekend for young women affected by breast cancer. They described this event as being valuable in terms of accessing information relevant to them and meeting others in a similar position.

"I found it quite rewarding really, meeting a lot of other women who were going through the same thing...I think it helps." – Ruth

The women interviewed found it difficult to access experiential support because of the lack of support groups aimed specifically at younger women. Some of the women had attended mainstream breast cancer or cancer support groups, but often they only attended once and found them to be unhelpful or even distressing.

"Going through it when you're fifty you've got a family, you've got kids, it's completely different! Like I've got no idea what it's like to be a fifty-year-old going through cancer. But a twenty-six-year-old, a thirty-year-old, going through it that

hasn't got kids, it feels like your whole future is in jeopardy, for different reasons."

– Naomi

"I'd overheard people say 'Well this has made us slow down, we're just chilling out now we're gonna have an early retirement and we're just gonna look after ourselves and have fun', and I was like 'Wow great, great for you, but my life needs to speed up now and get back on track.'" – Joanna

The young women found that they did not fit in at mainstream breast cancer support groups, or cancer support groups. They, therefore, felt neither the same as their peers, as evidenced in the previous section, but also neither the same as others with a history of cancer, because of their age and their different life experiences and concerns about the future. These findings suggest that health providers and breast cancer support services need to take into account the significance of age when referring patients to groups, and when providing support. Rather than being helpful, mainstream breast cancer support groups may be distressing for young women, and result in an increased sense of isolation.

Conclusion

The findings in this chapter have illustrated the extent and nature of biographical disruption for young women's lives during and beyond breast cancer treatment. The discovery of symptoms and deciding to see their GP was a process which involved challenging their own and others' assumptions about who is diagnosed with breast cancer, and also their assumptions about themselves as healthy young women. Four of the women reported finding GPs to be dismissive of their concerns because of their age, and they had to return on multiple occasions as a result of this ageism. Three women's experiences of being diagnosed during pregnancy illustrated that this engendered further discomfit, challenging their expectations about pregnancy and about new motherhood.

Uncertainty was found to characterise the women's experiences at the end of initial treatment. They found themselves to be neither ill nor well, neither identifying as cancer patients, nor as survivors. The fact of their age at diagnosis and the many decades ahead during which cancer could recur increased their anxiety about recurrence. These findings indicate that young women experience a liminal state after the end of initial breast cancer treatment. A further dimension of liminality, related to the young women's age, life stage, and pre-menopausal status at diagnosis, was that of the uncertainty which they experienced and perceived about their fertility and menopausal status. As a result of this, the young women experienced a loss of agency over their life course. The young women were unsure about when or if they would return to a pre-menopausal state, and also when and if they would be able to have children.

The young women's responses to the question of whether they used the term 'survivor' about themselves highlighted the burden of this uncertainty on their lives. The expectations which they, and others, held about the end of treatment made it difficult to communicate this uncertainty. The perception of the 'survivorship' period, they felt, precluded the expression of emotions such as pain, anger, or grief. Young women found it difficult to access experiential support which meant that, while many found their partners to be supportive, they were unable to gain the benefits of sharing their feelings of vulnerability and ongoing problems which they were dealing with in their everyday lives.

Chapter Eight – Young women’s accounts of the impact of gender and its intersection with other social divisions

Introduction

In the preceding two chapters, I have explored the young women’s accounts with respect to their embodied experiences and perceptions, and the significance of biographical disruption. In this chapter, I draw on the theoretical perspectives of feminism and intersectionality in order to explore how social divisions informed the young women’s lives. Previous research has identified the significance of gender for living with a history of breast cancer, and this chapter aims to explore young women’s perspectives, and to identify the distinctive features of young women’s accounts in the context of social divisions. There is also a growing area of research about the significance of intersecting oppressions for the experience of breast cancer, such as racism and heterosexism, and this study aims to contribute to this body of research by exploring it from the perspectives of young women. Intersectionality thus informed the theoretical framework and methodology for this thesis. This was reflected in the construction of the sample, as discussed in Chapter Five, although numbers of women who identified as minority ethnic or lesbian were small.

In this chapter, I begin by discussing how the young women’s accounts revealed the ways that conventional notions of gender and femininity informed their lives during and beyond initial treatment for breast cancer, and the ways that women described attempting to regain or maintain their gender identity. I also discuss the management of emotions which the young women performed in order to protect others around them, illustrating that this had a gendered dimension. Following this, I discuss the significance of age, as age and gender intersected to shape the impact of treatment on their fertility and on their experiences of

motherhood, as well as their accounts of their altered bodies. I then explore the accounts of black and minority ethnic (BME) and lesbian women, reflecting the third research question, which had a specific focus on the influence of racism and heterosexism. Following this is an analysis of the accounts of the two disabled women in the study. Finally, I consider the young women's accounts of the financial demands associated with breast cancer in the light of research which suggests that young women may be particularly affected by the costs which accompany treatment.

The impact of gendered appearance norms

Breast cancer treatment, as argued in Chapter Four, has the potential to “destabilise certain taken-for-granted meanings regarding gender, sexuality, and identity” (Rubin and Tanenbaum 2011:403). Previous research (e.g. Langellier and Sullivan 1998; Bredin *et al.* 1999; Connell 2005; Rubin and Tanenbaum 2011) has reported that many women experience and perceive a threat to, or loss of, their gender identity as a result of treatment, for example because of the effects of surgery on breasts, which are associated with feminine identity in Western culture (Yalom 1997; Young 2005). In this section, I explore the young women's accounts in relation to this.

Women's gendered experiences and perceptions of an altered body

In Chapter Six, I demonstrated how the young women struggled with changes to their bodies. This section builds on the embodiment analysis, exploring how these bodily changes were experienced in the context of gender norms and expectations about the appearance and composition of young women's bodies. In the young women's accounts, loss of femininity was strongly connected to the effects of treatment on the appearance of the body. Femininity refers to those qualities which are socially constructed as being associated with female identity. The term femininity was often used by the young women when they spoke about the changes to their bodies.

“[I’ve gained] two and a half stone so I feel pretty, pretty fat...I feel like a boy with my hair...So I feel like a fat boy.” – Beverley

“The risk of lymphedema, that worries me a lot as well, because I don’t want to have a big thick man arm.” – Kim

“It attacks the very core of you being a woman, so things like long hair: that’s gone. Um I had really, really long nails...They’re not what they used to be, they break really easily. My skin has changed, my body’s four stone bigger like I say, my nails on my feet are all discoloured from the chemo. Um, obviously when you take your clothes off that’s the biggest hit that y’know, you’re standing in the mirror and you’ve got one breast and one huge scar.” – Sarah

Evidently, the bodily changes which women experienced as an assault on their feminine identity extended much further than the loss of, or surgery to, their breasts. The young women identified a multitude of changes to their bodies as signalling a loss of femininity, and they felt as though they were “positioned outside ‘normal’ femininity” (Gilbert *et al.* 2010:405).

“I think because I don’t feel complete... [Even] when a girl meets another girl, you meet them and you just expect everything to be perfect, y’know what I mean? So I definitely feel less girly.” – Melanie

“Although I feel happy in myself I do look at other women and think ‘I wish I had a pair of boobs like that.’” – Beverley

Women also encountered explicitly sexist attitudes towards their decisions about preventative surgery:

“When I was going to have the bilateral mastectomy, my sister didn’t want me to have it. She’d had a single mastectomy and obviously it had had a big impact, and her husband told me that I was cutting off all the bits of me that made me a woman.”

– Vanisha

Some of the young women questioned their ability to be desirable to men after treatment because of its effect on their bodies, also found by Gluhoski *et al.* (1997), who interviewed women who were single at diagnosis.

“Do men really want to be with someone who has like one breast and one strangely fake artificial breast and who’s had breast cancer?” – Hayley

“I always look at guys who I think ‘Oh I’d definitely fancy you but you’d never be interested in me’ ...I’m much less confident in that respect and I just wouldn’t go there because I think they just wouldn’t.” – Melanie

Interestingly, some women said that they did not experience breast cancer as a threat to their femininity. Ruth and Vanisha, for example, both explicitly critiqued the idea that body parts constitute a person’s identity as a woman.

“I don’t feel any less womanly than I did before because I don’t think having ovaries and breasts make the woman...I think it’s what’s inside you and how you are.” – Ruth

“It depends on your political awareness doesn’t it? Y’know, I was a feminist before I was a lesbian so – in terms of how I view my body anyway...So many women, I think, their hair is bound up with their sense of femininity, their breasts, makeup, y’know all those kinds of things, and I think because I don’t attach importance to

them in that way, so I don't think at any point I thought my femininity was being attacked by this process that I was going through." – Vanisha

As Vanisha suggests, a woman's identification with feminist politics which challenge normative ideals of femininity may mediate the influence of such norms on her perception of her gender identity after breast cancer treatment. Rubin and Tanenbaum (2011) also found this in their study about lesbian women with a history of breast cancer. Both Ruth and Vanisha identified as lesbians, but other participants who identified as feminists also spoke about the way this shaped their experiences and perceptions.

"You have to imagine what you're gonna be like if your body is completely transformed, and if I didn't have any hair, and all the things you kind of associate with being ladylike...I think [being a feminist] made me braver about the prospect of it." – Evelyn

The identification with feminist politics may mitigate the impact of breast cancer treatment on a young woman's gender identity.

Maintaining or regaining a sense of femininity

The young women spoke about the ways in which they tried to maintain, or regain, their gender identity. Gender norms had an impact on the young women's decisions about their treatment and reconstruction. There was evidence that gender informed the interactions between the young women and their breast surgeons, also found by Rubin and Tanenbaum (2011) in the US.

"He [surgeon] was all for like giving me a sort of brand new boob and then I was gonna get this one all uplifted and all that kinda thing, but I just kind of sort of said 'no'." – Ailsa

Age may have intersected with gender in women's interactions with their breast surgeons. Younger women are more likely to undergo immediate breast reconstruction in the UK (Lawrence *et al.* 2011), and a study in the US found that surgeons discussed reconstruction more often with younger women than older women (Alderman *et al.* 2008). There were also indications in the young women's accounts that surgeons held age-related assumptions about young women's reconstruction decisions.

"They said 'Do I want a mastectomy, or do I want chemotherapy first, or do I want a reconstruction at the same time?' I said 'No just give me the mastectomy I'll sort anything else out, like reconstruction-wise, later on'. Um, they gave me four days to think about that, he said, 'cause of my age in case I changed my mind." – Beverley

Breast reconstruction has been presumed by the medical establishment to restore a woman's gender identity after breast cancer, a presumption which has been subject to much feminist critique (e.g. Lorde 1980; Young 1990; Batt 1994; Kasper 1995; Rubin and Tanenbaum 2011), because it places breasts and their appearance at the centre of women's gender identity. However, some women did speak about regaining a sense of their gender identity through breast reconstruction.

"I think y'know with [daughter] I, y'know just wanted to – oh God, I want say 'Look as normal' but that's probably – y'know, what's normal?! Y'know, but try and have something that, yeah, looked as much as y'know a woman's figure would do." – Dawn

"I'll have my reconstruction next year and I'll feel like a proper woman, not that I don't feel like a proper woman now but y'know what I mean, I'll feel like me again." – Beverley

Both Dawn's and Beverley's accounts indicate their awareness of the influence of gender norms on their understanding of themselves as women. Dawn identified that she wanted to look like a 'normal' woman for the sake of her young daughter. Connell (2005) in a study about young women with breast cancer, also reported that several women expressed wanting to look as much like 'normal' women as possible for the sake of their young children. The women's accounts in this study also revealed the possibility of reconstruction to restore more than only gender identity. Beverley above equates having reconstruction with not only feeling like a 'proper woman', but like 'me', indicating that reconstruction, for her, went beyond restoring her feminine identity.

My analysis of existing research in Chapter Four concurred with Thomas-MacLean (2005), who argued that previous research in this area has itself been shaped by gender norms, such as privileging appearance over sensation and physicality. Previous literature has shown that physicality is a major reason many women choose reconstruction (e.g. Langellier and Sullivan 1998). With this in mind, I took care to explore sensation and physicality in the questions asked and prompts used during the interviews, and also during the analysis. Some of the young women in this study reported that the sensation, or anticipated sensation, of physical discomfort due to lop-sidedness was a reason for opting for reconstruction.

"I hated it, I hated the unevenness." – Kim

A number of the women shared their fears about waking up from surgery with only a scar where their breast had been.

"I absolutely had to wake up with something there." – Tabitha

"I don't think I could have dealt with waking up with nothing there...Having nothing there at all really scared me." – Hayley

Reconstruction was, therefore, also a way of avoiding, or mitigating the physical and emotional loss experienced by women after mastectomy. The young women described other ways they regained a sense of femininity, such as through the use of makeup and clothing.

“I still wear dresses, and I think it’s how you dress that sometimes makes you feel more girly, but yeah you just feel a bit gross. Not gross but like a bit scarred.” –

Melanie

“I can still get dressed up and feel attractive and feel feminine when I get dressed up. So I’ll do my hair and my makeup and I’ll put nice clothes on and I’ll feel attractive. But then I guess if you take all of that away I don’t know. [Pause] If I was like, laid bare [Pause] you don’t look how you ‘should’ look in inverted commas.” –

Hayley

As the above accounts show, this sense of femininity was limited, and they often contrasted the appearance of their bodies naked with its appearance in feminine makeup and clothes.

Emotion work

In the literature review, I discussed the concept of emotion work, developed by Hochschild (1983, 2003), and its relevance for understanding young women’s experiences and perceptions of breast cancer. Emotion work is defined as the management of emotions – both one’s own and others’ – for the benefit of others. Research indicates that women are more likely to perform emotion work than men (e.g. DeVault 1991; Erickson 2005), because protecting partners and children from distress is perceived as integral to the woman’s role in the family (Duncombe and Marsden 1998; Hochschild 2003). Two studies about young women with breast cancer (Coyne and Borbasi 2007; Klaeson and Bertero 2008) reported that young women felt that they had to be emotionally strong for the benefit of others.

However, the researchers did not frame this as gendered emotion work, but rather in terms of

feeling required to be back to normal. Many of the women in this study described needing to manage their own and others' emotions during treatment, for the benefit of those around them.

"I was having to say to people 'It's alright, it's alright'. And they'd be the ones like kind of crying or whatever, and I'd be like trying to make everyone happy and at easy when in actual fact I should maybe have thought 'Do you know what? I'm the one going through this'." – Kim

"I was kind of being strong for my children I suppose and [partner] to a certain extent." – Ailsa

This emotion work continued after the end of initial treatment. Sarah told me that she did not share her ongoing concerns with her husband because he had been supportive throughout treatment, taking over her usual role in the family home.

"Rather than if affect both of us I'll just deal with it... 'Cause he was so good in that year of when I was going through most of the treatment...He literally just took the helm and sorted out the kids and anything to do with the school, y'know he'd go shopping every weekend, he'd do all the cooking, um, he was brilliant. So I just think now 'Just let him get with what he needs to do, I'm not sick anymore.'" – Sarah

The perceived responsibility to perform emotion work has particular implications for young women as they are more likely to have young children living at home, who they may feel need to be protected from distressing emotions. On the other hand, I also found that being younger meant that some women had children who were of such a young age that they felt they did not need to explain or discuss cancer with them.

“I think he’s a bit young he just wouldn’t really know what I was saying.” – Hayley

“I think because he was so wee...I didn’t really need to talk to him about it.” – Ailsa

Some of the women did have children who were living at home and were old enough to understand the situation, and I asked them how they dealt with this.

“My youngest is profoundly deaf...He was a bit shocked when I first lost my hair but...I wasn’t upset in front of him about my hair.” – Beverley

“I said ‘Please don’t worry about Mummy. Mummy’s not worried about losing her hair so you don’t need to be worried about Mummy losing her hair’. But, um, that was a really tough time actually that was, the hair loss bit.” – Charlotte

The women, therefore, often hid their feelings of distress from their children in order to protect them. Philippa, described a different approach, talking about her desire to be a good role model for her teenage daughter, which involved exposing her to struggles.

“I think your children need to understand how you deal with conflict, and how you deal with negativity, and how you deal with situations that are really complex and hard to swallow...Within reason I’ve got to say. The moments when I was wailing like a banshee when there was no one in the house: that’s just for me that’s my moment. But she knew when I was tired, she knew when I struggled.” – Philippa

As Philippa’s account indicates, she performed complex emotional work, and there were emotional moments which she hid from her daughter, but she also allowed her to see difficult times. I asked the young women in the advisory panel to consider why they, and so many of the interviewees, reported performing such emotion work. There was a strong

consensus that there was a gender dimension, and that, as women, they felt that they were the emotional pillar, central to the emotional wellbeing of their families.

Not all of the women felt that this emotion work left them without their own emotional outlet, however, as Lyndsey's account illustrates:

“People say it's bad to trap your feelings 'cause then they may come out at some point and blow up, I don't feel that.” – Lyndsey

This suggests that emotion work might be helpful for some women themselves, not only for others around them. Naomi, who spoke of staying positive for others, found that her partner was able to help her vent her emotions when they became too much for her.

“I wouldn't let it beat me so I'd bottle it all up, but then it would get too much and my boyfriend would be like 'Right time to let it out now'. He could see the tension in my body and he'd almost like make me cry 'cause he knew it would make me feel better.” – Naomi

The literature on emotion work indicates that women perform it more than men, and this study generally seems to support this gendered dimension. However, women did speak about the emotional support of their partners, and Naomi's account demonstrates that partners may also perform emotion work in this situation, but further research is needed to explore this fully.

The significance of age

I now consider how other oppressions also intersected with gender to shape young women's experiences and perceptions, beginning with age.

The impact on fertility

The previous chapter illustrated the impact of treatment on young women's identity as a result of its implications for fertility, and this section extends this analysis, highlighting the way that gender and age are interlocked. As illustrated in the literature review, studies have identified fertility as a significant issue for young women with breast cancer, and some women experience it as a loss of womanhood (Dunn and Steginga 2000; Wilmoth 2001; Klaeson and Bertero 2008). The ability to have children is viewed as central to womanhood (Yadlon 1997; Williams 2002), and the loss of such ability, or potential loss, may therefore have a profound effect on a young woman's perceived position in society, and her gender identity.

"How do you identify yourself as a woman? ...I'm losing my hair, I've lost a boob, and I can't have kids currently. And those are things that define you." – Tabitha

"The thing about not being able to have kids as well y'know, that's difficult, because that just takes away your, I guess your femininity, just a little bit more y'know." – Dawn

In the previous section I demonstrated how Vanisha experienced being told that choosing a preventative mastectomy would result in a loss of womanhood. Charlotte had an identified BRCA mutation, and had elected to have a hysterectomy to prevent uterine and endometrial cancer, and reported a similar experience to Vanisha:

"Lots of women have said to me oh, y'know, 'Hysterectomy: you're not a woman anymore' ...I've had people say that to me, or maybe not like that, but 'I wouldn't feel like a woman anyway' is what people say." – Charlotte

This illustrates that defining a young woman's gender identity goes beyond the outer appearance of the body, and extends to its inner organs threatened by breast cancer treatment.

Being a young mother

Although women of all ages can be mothers when they are diagnosed with breast cancer, there were specific features of being a young mother and having breast cancer. For example, when Hayley was diagnosed, her son was less than twelve months old, and the surgery on her breast and lymph nodes left her unable to lift him during recovery.

"I couldn't be by myself with [child] for like six weeks...Not being able to care for him was really heart-breaking...In the nights occasionally he'd wake up crying and I couldn't go to him because there was nothing I could do 'cause I couldn't lift him out of his cot." – Hayley

Hayley spoke candidly about the difficulties of looking after a small child during gruelling chemotherapy treatment:

"I hate to even verbalise it, but there were times when I thought 'God, this is really hard going through this with a young child, and if I didn't have him to worry about or to think about that responsibility, then it would be easier to cope'." – Hayley

Hayley's account highlights the difficulties of being diagnosed while taking care of a very young child, an experience which is distinctive to young women. Hayley was able to ask her husband and extended family for help, but not all young women will have such a strong support network throughout treatment.

A number of the young women had said they had considered adoption at some point since treatment, or were still considering it, and Kim and her husband had successfully adopted two children several years after her diagnosis. Gemma and Kim both felt that they had been discriminated against in their experiences with the adoption system. Gemma recalled a conversation with a person at the adoption agency about when she could apply.

“He basically said ‘Well it’s five years...Try back in 18 months but I wouldn’t hold your breath’...And I was really upset after that ‘cause I thought maybe it might not such a big issue.” – Gemma

The British Association for Adoption and Fostering (BAAF) guidance states that everyone who applies to adopt must undergo a medical examination, and health issues are considered when applications are processed, but people who have had cancer are not automatically ruled out (BAAF website, accessed February 1st 2015). Adoption agencies, clearly, must put the interests of children before those of potential parents, but young women may well perceive such treatment, as described by Gemma above, as discrimination when going through the adoption system. Being denied the possibility of adopting as a result of breast cancer treatment may be seen by young women as further evidence of their position in society as women, devaluing them as potentially good mothers.

Normative gender ideals about fertility and motherhood, therefore, informed the young women’s experiences and perceptions, and the impact of treatment on their ability to have children and care for them constituted a further threat to their gender identity, which older women whose children have grown up may not have to face. This extends previous knowledge by exploring how ageism and gender oppression intersected in the young women’s accounts of fertility and motherhood after breast cancer.

Ageism in the young women's own perspectives

There was evidence in the young women's accounts that their own ageist assumptions shaped their experiences and perceptions, and it was suggested that older women might be less concerned about the changes to their appearance.

"You are a bit more particular about your appearance and stuff maybe when you're younger." – Lyndsey

"Whenever someone sees my reconstruction, like any doctors or like, they're like 'Oh God, I've done such an amazing job!'; and I just feel like saying to them: 'Fuck off' ...I've never seen anyone else's, so yes maybe it is great compared to all the other people who are like 50 or 60 or whatever, but...I shouldn't have to deal with this." – Melanie

The young women in Connell's (2005) study also felt that younger women were more exposed and subjected to cultural and beauty norms. Melanie expressed a sense of injustice that she should have to worry about issues such as lymphedema as a young woman:

"When you're young and it's summer and you work in a hot office you just want to take off your cardigan and wear a vest top. I'm very conscious of my arm and it's just ridiculous, I'm in my twenties and my early thirties, I shouldn't have to worry."
– Melanie

This illustrates that the young women's experiences occurred within a context which has particular expectations for young women's and older women's bodies. It also suggests that these expectations increased the young women's suffering after treatment. Sarah, however,

argued that older women would still be distressed by breast loss and would still be sexually active, although even her still account showed a degree of ageism:

“A fifty-year-old woman would still look in the mirror and see one breast and think ‘That’s not right’ and y’know not – just because you’re fifty doesn’t mean you’re not intimate with your husband....And even at sixty if you’ve still got it y’know what I mean?” – Sarah

Such ageist assumptions may have been a further barrier to young women accessing the experiential support they needed because, as illustrated in the previous chapter, they often felt that support groups would not cater to their particular concerns, and therefore they did not attend them. To be diagnosed with breast cancer at a young age was often seen as more difficult compared to the experiences of older women, because it was perceived to be particularly unjust and unfair. The young women drew on ageist attitudes and stereotypes about older women, and the young women’s experiences of an altered body were perceived to be *harder than* rather than *distinct from* those of older women. Social expectations about gender and age were, therefore, interlocked in the young women’s experiences and perceptions of life after breast cancer, and informed their experiences of their changed bodies.

The experiences and perceptions of black and minority ethnic women

The three BME women interviewed – Sarah, Tabitha, and Vanisha – identified how intersecting aspects of their identities shaped their experiences of breast cancer. The three women had diverse cultural and ethnic backgrounds. Sarah identified as mixed heritage, with one white British parent, and one African-Caribbean parent. Tabitha identified as African-British, and Vanisha as Indian. This section explores their accounts, showing that

they had diverse and distinctive meanings about hair loss, and that they identified a profound lack of support for BME women.

Black women's meanings attached to hair loss

I began this chapter by exploring how gender was significant in young women's accounts of bodily changes as a result of breast cancer treatment. Ethnic identity also shaped women's experiences and perceptions of changes to appearance in complex ways. It was felt that, while hair loss might be distressing for all women, it has particular meanings for black women.

"I think for black women as well, um, our hair is very, very personal, um so when we lose it it's just like 'Oh my God', and I think that for most women losing their hair would just be – it's your crowning glory isn't it? It's your womanness." – Sarah

Tabitha argued that the loss of control about how she managed her hair was very distressing, and linked this to her identity as a black woman.

"Hair for black women is quite a sensitive issue, we do all kinds of things to manage the hair, manage the 'fro...When you look at black women we've all got either really short hair, long fake hair, y'know Beyoncé with her different wigs and everything, or you go natural, or it's braided. But when you don't have control of that that's quite hard." – Tabitha

Interestingly, she went on to argue that being a black woman meant that it was actually easier for her to control how others perceived her, being able to 'pass' as well.

"I was able to go out and because black women have so many different hairstyles...People didn't realise that I was poorly...That's what I want you to see: a

woman walking down the street, not someone who might be ill, or has got alopecia or breast cancer.” – Tabitha

The accounts of the BME women in this study therefore suggested that hair loss has distinctive meanings for black women, and also that being a BME woman had implications for managing hair loss.

Lack of support and invisibility to one another

Sarah, Tabitha, and Vanisha all felt that there was a distinct lack of support for young black and minority ethnic women experiencing breast cancer.

“There’s definitely a support gap for black women...There’s black women out there with breast cancer, there’s got to be, but you don’t see them, they don’t make themselves known.” – Sarah

Sarah argued that cancer is approached differently by BME women:

“In ethnic minorities, cancer, not even just cancer, generally, we’re very, very secretive, and very inward with illnesses, we don’t share as much as European white women.” – Sarah

Tabitha also experienced this cultural secrecy and sensitivity about breast cancer in her family.

“I said to Mum that ‘You need to let your sisters know – my aunties – know and my cousins know, or do you want me to?’ ...She said ‘I don’t want people to be talking about it because everyone is gonna think you’re dying and I don’t want them feeling sorry for me’ ...It’s partly pride and it’s a respect thing, and it’s a perception thing

that you have to be seen in a certain way, in a certain light, and basically they want to be seen as perfect, and that is a cultural heritage thing.” – Tabitha

Previous research (Patel *et al.* 2014) has reported that BME women feel cultural pressure which prevents them from sharing their experiences of breast cancer with others, and their participants felt that it was important to try to overcome such secrecy in order to help other BME people with cancer, and improve awareness of cancer within minority ethnic communities. One of my participants, Sarah, had kept an online blog about her experiences because she wanted to break down the cultural secrecy surrounding breast cancer in BME communities.

Chapter Seven showed that the young women found it difficult to access experiential support because of the lack of support groups catering to young women. Tabitha expressed disappointment with her local cancer centre, which had dropped their support groups for younger women and for BME women soon after she was diagnosed. Support groups made up of mainly white women were not perceived as able to offer support and advice for minority ethnic women struggling with issues specific to their cultural and ethnic background. Tabitha spoke in detail about the bodily changes caused by breast cancer treatment and the ways that dealing with such changes was distinctive for her as a black woman, such as the need to moisturise:

“I found with the whole chemo thing that my skin just dried out and I looked quite ashen if I didn’t moisturise, but then what do you moisturise with? Because there are certain ingredients that you should avoid...I had to work it all out for myself because I didn’t have anyone else to ask, to turn to.” – Tabitha

In a recent study of British black and South Asian women, Patel *et al.* (2014) also found that BME women with breast cancer expressed a preference for support from women whom they

could relate to culturally. The age range of Patel *et al.*'s participants at diagnosis was 42-60. My study builds on their findings, showing that young BME women required information and support, but had difficulty accessing such support because groups which catered to BME women were difficult for women to find, *let alone* those which catered to *young* BME women.

Vanisha, who identified as a black lesbian, found it even more difficult to access experiential support.

"I went to one meeting where, of course, I was the only black woman...During the whole [experience] I didn't meet any women who I knew to be lesbian women...I have a friend, a black lesbian who has a friend – another black lesbian – who went through breast cancer shortly afterwards but I haven't met her, I just know of her...There is something about isolation." – Vanisha

Vanisha also felt that information about breast cancer from charities and the NHS did not represent her.

"It doesn't reflect me as an Asian woman usually, because it's usually images of white women and if there are black women they're towards the back pages." – Vanisha

There were, therefore, ways that different identities intersected to prevent women from gaining access to the experiential support and information which they required, and BME women felt that there must have been other BME women with breast cancer but they remained invisible to one another. This led to a profound sense of isolation, as Vanisha's account illustrates. I now turn to the distinctive experiences of the two lesbian women in the sample.

The experiences of lesbian women

Two women who identified as lesbians were interviewed in this study. Other women in the study may not have identified as heterosexual, but only Ruth and Vanisha disclosed their sexual identity to me. There is very little evidence about the experiences and perceptions of young sexual minority women with breast cancer, and this study aimed to be inclusive of lesbian women's accounts. In this section, I explore the heterosexism which the lesbian women reported experiencing in the health and care system.

Heterosexism encountered in the health system

Ruth and Vanisha each had quite different perceptions of how their lesbian identity had shaped their experiences of breast cancer. Ruth did not feel that being a lesbian had had much impact on her experience, whereas Vanisha spoke extensively about heterosexism she encountered in the health system, throughout and beyond initial treatment.

“I had one nurse who was, who I'd never had before, a breast cancer nurse, this was after all the treatment, and she was talking to me about sexual intercourse, so I just kept, I just thought ‘Okay I'm gonna stare at her blankly’ until she went out of the room and then she came back and was completely different. She must have gone and checked the notes.” – Vanisha

Previous research has found that the assumption of heterosexuality on the part of health practitioners often prevents lesbians from being able to have meaningful communication with them about their experiences of breast cancer treatment (Fish 2010). Such interactions as that described by Vanisha above, may not be viewed as heterosexist by heterosexual women, but the position of sexual minority women reveals the assumptions about sexuality embedded in these interactions (Fish 2006).

Ruth did speak about the lack of options to identify as civil partnered on NHS forms:

“There’s not room on there for ‘civil partner’ and there should be, so it really pigged me off ‘cause you can’t say ‘married’ ‘cause you’re not allowed to legally say ‘I’m married’ even though that’s what it feels like.” – Ruth [Reflecting legal position at time of interview (2013)]

The lack of space for civil partnered on NHS forms invalidated Ruth’s experience of her relationship. Ruth had also anticipated negative reactions from others in her support group, but found that she did not encounter any.

“They said ‘Oh are you married?’ and I said ‘No my partner’s called [partner]’ and they’d go ‘Oh right!’ And they’d just carry on like, well it didn’t matter, and I were shocked.” – Ruth

Vanisha had needed to have a flu vaccination before beginning chemotherapy, and normally a co-habiting partner would also be encouraged to have the vaccination, but because of their complicated living arrangements, Vanisha’s partner was not able to access this.

“People assume that if you’re in a relationship you should be living in the same household, and here she was living with her ex-husband and her children and the fact that I was staying there during the chemo, systems don’t allow for those complexities really and the reality of the way lots of people live.” – Vanisha

Vanisha also found that, as well as not reflecting her as an Asian woman, breast cancer literature also did not reflect her as a lesbian.

“The Breast Cancer Care literature... This must be a couple of years ago, one of their publications on sexuality and intimacy [laughs] I kind of scrawled all over it what they needed to change, because it just assumed intercourse all the way through and so on, and that you had a male partner.” – Vanisha

Fish (2010) also found that participants reported difficulty finding information relevant to them as lesbian and bisexual women. In this case, Vanisha’s intersecting identity as a young, minority ethnic, lesbian woman produced a particular position from which she found it difficult to access experiential support and information which she felt reflected her.

I noted in the literature review that intersecting structures of discrimination cannot straightforwardly be isolated and examined separately, but should rather be viewed as intermeshing to produce an experience unique to that position (Collins 1998; Thiara and Gill 2010). Vanisha spoke about her experiences in the health system and the ways that her identity as an Indian woman and a lesbian shaped people’s assumptions about her:

“As an Indian woman, are people more likely to assume that I’m straight? Less likely to think that I might be a lesbian? What are the assumptions that medical professionals are likely to make about me because I’m an Indian woman? What do they think my family life is like, my experience?” – Vanisha

These findings demonstrate that the lesbian women faced particular oppression in their experiences in the health system because of assumptions about heterosexuality, and also that this intersected with other social divisions, such as ethnic identity. I now consider the experiences of the two women who identified as disabled before their breast cancer diagnosis.

Disability and breast cancer

The social model of disability emerged out of the disability rights movement in order to raise attention to how people are disadvantaged by social organisation and structure (Oliver 1983), and commentators from within a disability rights perspective have also since focused on how people experience impairments which shape their everyday lives (Shakespeare 2006; Wendell 2006). These perspectives inform the understanding of disability in this thesis. In this section I explore the accounts of the two young disabled women in the study.

Being a disabled woman with breast cancer

Research has explored access to breast cancer screening, quality of care, and survival rates for women with physical impairments or learning difficulties (e.g. McCarthy *et al.* 2006; Liu and Clark 2008; Truesdale-Kennedy *et al.* 2011; Iezzoni *et al.* 2012), but the experiences and perceptions of young disabled women living with a history of breast cancer are under-explored. There were two women in this study who identified as disabled: Ruth and Charlotte. Ruth had experienced a back injury in her late 30's, and Charlotte had been a wheelchair user her whole life. The range of impairments and people's experiences of disability are diverse, so these findings are limited, but nevertheless contribute to the small amount of research in this area.

The treatment-induced menopause had particular implications for Charlotte and Ruth, because of the impact on bone density loss. Ruth had experienced an injury to her back several years before her diagnosis, and as a result had to stop working. She found that her injury had considerably worsened since entering the menopause during chemotherapy.

“It's lack of oestrogen, so I'd say it's deteriorated more in the last seven years than it had before, it was reasonably stable before.” – Ruth

Charlotte used her arms and hands to be mobile, and this had an impact on which long-term treatment was recommended by her oncologist.

“They’d normally put me on that, they’d put me on the postmenopausal ones [medication], but because of the risk of you getting joint pains, and I already get quite a lot of problems – elbows and shoulders – because of the hammering they’ve taken over the years, he said ‘I’m not gonna risk it’.” – Charlotte

Charlotte had entered a permanent menopause after having her ovaries removed, but her doctors kept on her on the pre-menopausal medication – Tamoxifen – because of the worse risk of joint pain associated with Arimidex – the post-menopausal preventative treatment.

Charlotte felt that being a disabled woman and experiencing hair loss, had particular meanings for her in terms of coping with the loss of femininity, and she experienced it as a profound threat to her identity as a woman.

“From a disabled person’s point of view...My boobs were the thing that kind of made me feel female if you like really, well, and my hair. To learn that I was gonna lose my hair and lose my boobs it was quite a tough time actually...I’ve gone through my whole of my life with a body that looks different to everybody else’s, you get used to being pointed at and stared at and children asking you questions and all that kind of thing. But being a bald person with a disability was something that I never wanted to have to experience really.” – Charlotte

This illustrates the particular social position in which Charlotte, as a disabled woman was located, and the particular meaning which breast cancer treatment held for her as a result. Charlotte later spoke about the social construction of disability in relation to expectations which people held about her going through cancer:

“You would expect a person with a disability to be quite fragile really I suppose, and then when you get a life-threatening illness as well. But I dunno something just keeps happening and I keep coming on out through the other side.” – Charlotte

Charlotte was one of the few women in the study who held a positive perception of the term ‘survivor’, partly because it adequately described her experiences of hardship from birth. She was able to draw on it to challenge the social constructions about disabled people, such as their fragility.

Exploring the accounts of the two women who identified as disabled illustrated the particular meanings of having breast cancer from the position of a disabled woman. It also highlighted the particular implications of treatment-induced menopause for women with physical impairments. I now consider how the financial circumstances of the women affected, and were affected by, breast cancer.

Financial demands of breast cancer for young women

During the interviews, I asked women if they could speak about how breast cancer had affected their finances and how they felt their financial position at diagnosis had shaped their experience. As highlighted in Chapter Four, research has shown that there are differences in stage at diagnosis, and incidence and survival rates, associated with socio-economic inequalities in the UK (Adams *et al.* 2004; Bray *et al.* 2004; Lawrence *et al.* 2011). The women in this study were from diverse social and economic circumstances, as Table 3 (p.98) in Chapter Five illustrates. Reports published by Macmillan (2006, 2013) have indicated that there are financial demands associated with breast cancer treatment, and Macmillan’s findings (2013) imply that younger women may be particularly affected because the groups hit hardest in financial terms were found to be those with dependent children, and those working full- or part-time, because of the combined loss of income and costs of supporting a young family. When constructing my sample, I did not aim to recruit women from particular

socio-economic circumstances for reasons detailed in Chapter Five, but I aimed to explore the young women's accounts of the financial impact of cancer. I found that the financial impact of breast cancer, and the threat of recurrence, affected young women's perceptions of the future.

The extra costs of breast cancer

Macmillan (2013) found that four in five people with cancer in the UK were, on average, £570 worse off per month, due to loss of income, and extra costs such as heating the home during the day, and transport to hospital. The extra costs of having breast cancer affected a number of the young women, and these included transport to hospital during treatment, but also further expenses after the end of initial treatment, such as purchasing often extremely expensive clothing after surgery.

"I was like 'Oh I've got to get a swimming costume, what do I do about that?', and I go online and they were like eighty pounds and I was like 'That's really scandalous', they're actually cashing in on people that have had breast cancer...I would never in a million years pay eighty pounds for a swimsuit if I hadn't had the operation." – Gemma

Evelyn had become particularly concerned about preventing recurrence and leading a healthy lifestyle after treatment, and she spoke about the costs of this.

"I bought a new juicer and things like that, because I kind of think 'Well what can I do?' I bought some new trainers so I could run and I kind of, I bought books about it." – Evelyn

Some of the young women were able to rely on their parents for financial support and assistance for particular treatments, which older women, and women from more disadvantaged backgrounds, may not be able to do.

“My first surgery, um y’know they wanted me to wait three weeks and that was just too long for me to wait to have it out, so my, um, my Dad paid for me to have that one privately.” – Dawn

“[I] had to pay for it [IVF treatment] and I think in the end it was like six grand, and my Dad had to pay for it.” – Naomi

The NHS only offers emergency IVF treatment to women diagnosed with breast cancer when they are over the age of 30, and this meant that Naomi’s father had to pay for hers, while Kim was not able to access it at all.

“We were offered IVF before treatment started but because I was 29 and not 30, and yeah. And we’re talking like thousands ‘cause we would have had to pay for the eggs taken out, the embryos made, and then stored for X amount of years.” – Kim

Beverley wanted a preventative oophorectomy but she did not have access to this on the NHS because she did not have an identified BRCA mutation.

“If they say no [to an oophorectomy through the NHS] I might think about, it’s about four grand so it’s a lot of money but it’s probably do-able with a loan.” – Beverley

Financial circumstances and NHS rationing, therefore, meant that many of the young women were not able to access the surgeries or treatments to reduce their risk or help with their future reproductive choices.

Impact on income

Macmillan (2006) found that where the cancer patient was aged under fifty-five, seven in every ten households experienced a loss in income. All of the women who were employed when they were diagnosed were able to access some form of sick leave, but a number of them reported having to return to work sooner than they would have liked to because of the drop in pay, and many suffered financially.

“I had some time off then when I had my surgery I was straight onto 80% pay. And then I did go down to 40% pay which was near the end of my chemo.” – Beverley

“I was just lucky that I had six months full- and six months half-pay, but that’s the reason I went back to work, ‘cause we were then gonna have nothing.” – Kim

The group of young women had diverse social circumstances, with some being students at diagnosis, or early in their careers, and others about to take maternity leave when diagnosed. The women who were pregnant at diagnosis felt that they were in fact fortunate in one sense because they did not have to take sick leave as they already had maternity leave scheduled.

“I’ve been on maternity leave this whole time when I’ve been having treatment so I’ve never had any sick leave or anything.” – Catherine

One woman, Joanna, was a student when she was diagnosed. She said that this had both positive and negative implications:

“I was lucky in the sense that I wasn’t already in work and then having to take time out...[But it meant] an even longer amount of time of me not being able to contribute, my husband had to support me.” – Joanna

Being a student meant that Joanna had no access to sick leave or benefits. She applied to Macmillan for financial help and was able to access £200 from them which she said helped with bills.

A few of the women reported discrimination in their employment after breast cancer. For example, Tabitha was made redundant from her job soon after returning to work:

“I’d gone back after post-surgery and two, three weeks after that I was told my job no longer existed. The only person in the whole ninety-strong company. So basically what happened was an unfair dismissal discussion, which was resolved.” – Tabitha

Tabitha’s redundancy occurred at the same time as beginning Tamoxifen, and she found this to be an extremely stressful time because of the side-effects she was suffering.

The financial impact of having had breast cancer was therefore significant for many of the young women, and a number of them shared their concerns about future stability and the threat of recurrence.

“We’ve adopted these children, and if it comes back, well, we’ve adopted them, we’ve chosen to have them, and then what if something happens to me? Y’know I’m the one that earns the money, I work full-time, my husband’s part-time now because I earn four times what he earns. And if he didn’t have my income he couldn’t pay the mortgage, so y’know there’s a lot of worry about the future in that sense.” – Kim

“I also became very aware that I could be plunged into poverty...I put twelve grand away...I did become really quite worried about money and how I would survive if I get secondary cancer.” – Vanisha

This section has explored the significance of financial circumstances in the young women’s accounts of their experiences and perceptions of living with a history of breast cancer, demonstrating that the financial impact of breast cancer affected the young women across diverse circumstances. The young women’s accounts highlighted the extra costs of having breast cancer, which stretched beyond initial treatment.

Conclusion

The analysis in this chapter has demonstrated the ways that the young women’s lives, during and beyond initial treatment, were shaped by the intersection of gender, age, and other social divisions. The young women had to negotiate sexist norms and ideals about their bodies, and encountered explicit criticism when they made decisions about reducing their risk of cancer. The young women also performed complex emotion work for the sake of those around them, which has not been explored in previous research. Age was interwoven in their accounts of gender, as the implications for their fertility further threatened their femininity, and their potential to be good mothers was brought into question. They also held ageist assumptions that older women would be less affected, and that to have to manage such bodily changes at their age was an injustice. The accounts indicated that identification with feminist politics may mitigate the impact on a young woman’s gender identity.

The analysis of the accounts of the minority ethnic, lesbian, and disabled women, illustrated that their particular social positions produced distinctive experiences of living with and beyond breast cancer. A major support gap was identified by the young BME and lesbian women, and the BME women felt that they were not visible to one another. The lesbian women encountered heterosexism in the health system, which shaped their interactions with

health professionals. Receiving treatment as a disabled woman had particular implications related to the impact of treatment on mobility and pain. The perceptions of disabled individuals as fragile meant that Charlotte felt able to draw on the survivor identity positively. An analysis of the financial impact of breast cancer for young women indicated the extra costs which the women incurred as a result of treatment and beyond, and the implications of this on their concerns about the future.

This chapter builds upon the analysis of the previous two chapters, demonstrating that the impact of breast cancer on the young women's embodied experiences and perceptions, and on their identity, occurred in the context of intersecting social expectations, norms, and oppressions. This study aimed to be inclusive of the voices of minority ethnic and sexual minority women, and, although the numbers in the sample were small, the analysis contributes to this area of knowledge.

The next chapter contains a short discussion of the ways that the three dimensions of the theoretical framework overlapped, and the significance of what can be revealed by exploring all three elements of the analysis together.

Chapter Nine – *“It just literally pulls you apart in every possible direction”.* Combining the three analytical dimensions of the theoretical framework

Introduction

The preceding three chapters have demonstrated the profound and far-reaching impact of breast cancer on the young women’s lives, illustrated by the quote from Sarah’s interview in this chapter’s title. The aim of this short chapter is to consider how the three themes analysed – embodiment, biographical disruption, and gender and other social divisions – were interrelated in the young women’s accounts, and to explore what further insights can be gained when the ways that they overlap are explored. I will discuss three key examples from the study’s findings which illustrate the ways that the dimensions of the theoretical framework combined.

This chapter begins with a discussion of the accounts of the three women who were diagnosed during pregnancy – a phenomenon exclusive to young women, and which raised issues across all three key dimensions of experiences and perceptions that I have analysed in the preceding chapters. It shaped their bodily experiences, caused biographical disruption, and had implications for their gender identity, as will be explored in this chapter. I then consider the ways that interactions between the key dimensions occurred, presenting an account of how bodily experiences and gender norms informed women’s experiences of biographical disruption and liminality. The chapter ends with an exploration of the cumulative impact of having breast cancer as a young woman. Demonstrating that breast

cancer had far-reaching consequences for the young women and affected all aspects of their lives, the impact of treatment-induced menopause is highlighted.

Diagnosis during pregnancy: spanning the three key dimensions of experience and perception analysed

Being diagnosed with breast cancer during pregnancy is an experience unique to young women, but there exists almost no research on the subjective meaning of the phenomenon. The accounts of the three women in this study diagnosed when pregnant – Catherine, Dawn, and Lyndsey – revealed the profound impact.

In Chapter Six, I explored the women's accounts of their experiences of diagnosis and treatment while pregnant, illustrating that the threat posed by diagnosis was a threat not only to their bodies, but also to their baby's bodies, and that the anxiety and emotion which this raised was experienced through the body. After waking up from surgery, Lyndsey placed her hands on her bump and felt the foetus move, which reassured her that the baby was okay.

Being diagnosed during pregnancy was biographically disruptive, as explored in Chapter Seven. The young women found that being diagnosed with breast cancer spoiled what should have been a happy stage in their lives, disturbing how they had foreseen their pregnancies progressing, and interfering with their lives as new mothers.

The emotions raised by the diagnosis and treatment, and the limitations placed on their lives as a result of treatment were experienced in the context of gender relations. Diagnosis during pregnancy precluded the opportunity to have emergency IVF treatment and embryo preservation. This placed a further limit on the possibilities for their future, as well as being experienced in the context of gender norms about fertility and womanhood. After surgery, women are advised not to lift anything heavy, and so the women struggled to hold their babies or support them to feed them. Not being able to care for their young children, and

also having the option to breastfeed taken away from them had implications for the young women's position as mothers. Catherine resented this, saying that she felt that breastfeeding was *"the right thing to do"*. All three women had to give birth to their children prematurely in order to begin treatment, which not only disturbed their expectations for the circumstances under which their child would be born, but also raised significant fears about the impact of this on their children. They had all been initially concerned about their child's welfare, but all emphasised to me that their children were doing well:

"Since coming out of intensive care, there's no sign that he was premature, he's bigger than most boys." – Lyndsey

"There's nothing wrong with [child], you wouldn't know she was prem or had been through all that strife originally." – Dawn

"She was fine, she was seven pounds five, so she would have been massive if she'd waited full term...That's a normal weight." – Catherine

Dawn went on to say that she could not afford to be too ill during treatment:

"I could never sort of allow myself to be that poorly really because, um, because I had to be fine, I had to be okay to look after her really. Um, and y'know she's still here, which is proof that I did an okay job I guess!" – Dawn

These accounts further illustrate the significance of gender, suggesting that the women perceived a threat to their position as good mothers as a result of having to give birth early, and receive breast cancer treatment when their children were very small. They were, therefore, looking to their children's bodies and health as signs that they had not been

affected by their mother's treatment. This reflects the tensions which being pregnant at diagnosis raised between treatment and mothering.

Being diagnosed with breast cancer when pregnant raised significant decisions and emotions, and the young women's accounts revealed the impact of such an experience. The women in this study did not have to make a decision about whether to continue their pregnancy, but the experience nevertheless resulted in biographical disruption, and a threat to their identity as mothers. In previous literature, women diagnosed during pregnancy have been mostly absent from research. The accounts of these three women extend the small amount of research about this experience.

Interaction between key dimensions to women's experiences and perceptions

There were multiple ways that the key dimensions interacted with one another to shape the young women's lives with a history of breast cancer. Here, I explore the significance of the body and gender norms for young women's perceptions of liminality and biographical disruption.

The young women's accounts showed that the initial diagnosis was difficult, not only because they felt they were too young, but also because it did not make sense with how they felt in their bodies.

"I feel like I would be one of the last people to be diagnosed with breast cancer...I've always been like 'little Mel', how can cancer get into my little body?"

– Melanie

"I wasn't sick, I was in the prime of my life, I was healthy, I was fit." – Sarah

This can be understood as a ‘dys-embodiment’ experience (Williams 1996:23). This refers to the idea that, in normal everyday life, individuals have a largely taken-for-granted experience with their body, but through an event such as illness, the body becomes problematic, and a person becomes alienated from their body. They had felt well in their bodies: how could it have been that they were actually ill? The diagnosis thus undermined their trust in their bodily knowledge, and this left them wondering how they would know if they experienced a recurrence. After the end of initial treatment, the young women found that medical knowledge could not define them as cancer-free. This was an important contributing factor to their liminal state, because they were no longer a cancer patient, but they also did not feel certain that they were cancer-free.

As evidenced in Chapter Eight, as a result of treatment, many of the young women experienced a loss of, or threat to, their gender identity because of the cultural association of particular parts of the body and bodily appearance, as well as fertility, with womanhood. This shaped the nature of the young women’s sense of biographical disruption. The women had to re-assess previously taken-for-granted assumptions about their life course that were associated with their identity as women, and this compromised their position as women in society because of the loss of such possibilities associated with gender identity. Pregnancy and regaining fertility after breast cancer may, therefore, be understood as a way of not only returning to an anticipated life trajectory, but restoring a young woman’s gendered identity. Naomi, for example, felt that becoming pregnant, and fulfilling her lifelong dream of being a mother, would be the point at which she could say she had moved on from breast cancer.

Melanie’s account below particularly illustrates how the implications of treatment, in the light of gendered assumptions about how young women’s bodies should look, feel, and function, disrupted her life course and informed the nature of her sense of liminality. For Melanie, who was single, and whose hair did not fully grow back after chemotherapy, the dissonance between her body and expectations about young women’s bodies, caused her to

feel that she could not keep up with those around her in terms of reaching the same life goals, such as meeting a partner, as this long extract illustrates:

Melanie: *“I wasn’t really confident about relationships and then it [breast cancer] made it ten times worse so that was quite hard, um, and I just felt like, I felt like I was watching everyone’s lives just pass me by, um, especially while I was going through it but even afterwards I think, um, I just felt like I was way behind and it was really difficult to sort of catch up.”*

Sophie: *“So how do you feel now, do you still feel like that?”*

Melanie: *“No, I’m definitely getting there now, my hair was a really big [issue], I know it sounds, I feel ridiculous when I say it, but I think for a girl when she’s young and seeing all these, I always look at girls and think ‘I hate you’ like with all this nice, lovely hair ‘cause I think you don’t realise how feminine your hair makes you feel and I think also like men they look at your hair like it’s natural, it’s part of your face, and it really used to get to me. Um, but I definitely think that I’m getting there with that, I’ve spent a long time researching how I can sort it out, and I’ve gone to like millions of people, so I’m definitely getting there with that.”*

This account illustrates the interactive effects of the key dimensions of experience and perception on each other. The long-term effects on her body, and the impact of this on her gender identity, contributed to the disarray to, and suspension of, Melanie’s life course. Melanie compared herself with other women, and felt that she would find it difficult to find a partner because of gendered expectations and the effect of treatment on her body. She felt that she could not return to her anticipated life trajectory, catch up with her peers, and feel feminine, until the appearance of her hair had been restored. Melanie had spent a great deal of time, energy, and resources, on her hair, so that she could feel that her life had resumed a normal course.

Experiences and perceptions of their bodies and gender ideals, therefore, shaped the nature of the liminality and biographical disruption which the young women experienced.

Diagnosis had undermined their trust in their bodily knowledge, and medical knowledge could not definitively say that there were no cancer cells in their bodies, and this contributed to their sense of being neither a cancer patient, nor cancer-free. The young women's sense of biographical disruption and liminality was also shaped in the context of an altered body and gendered assumptions about women's bodies. The young women found that their lives could not resume their anticipated trajectory until their bodies could look or function in the way that was expected of them.

The cumulative effect of breast cancer on young women's lives

As I have illustrated, the experience of living with a history of breast cancer had far-reaching effects, impacting on every aspect of the young women's lives.

"Since [the end of initial treatment] it's just been a case of, um, dealing with the aftermath of it I guess, just, y'know, trying to get your life back on track, 'cause it's not just about the health issues, it just literally pulls you apart in every possible direction." – Sarah

The survival rate for breast cancer has been improving dramatically since the 1970's, and is now one of the highest survival rates of all cancers in the UK (Cancer Research UK 2014b). This is clearly a positive development. However, as the young women's accounts in this research have revealed, living with a history of breast cancer brings with it distinctive profound, pervasive, and long-lasting effects on young women's lives. One of the most significant issues which emerged from the accounts, and which highlights the cumulative impact of breast cancer on young women's lives across the three broad dimensions, is that of the experience of treatment-induced menopause, and the effect of hormonal and chemical treatment on the young women's fertility. As illustrated respectively in preceding chapters,

treatment-induced menopause added to women's sense of dissonance between the expectations and the reality of their bodies as young women, caused previously taken-for-granted assumptions about their lives to be challenged, and impacted on their gender identities.

The experience of being a young woman with breast cancer, therefore, brought to the fore, not only the gendered assumptions about young women and expectations about the life course, but also the way that a woman's ability to fulfil desired social roles, such as motherhood, is contingent upon the workings of the body. The power of the body to foreclose "future biographical possibilities" (Boughton 2002:429), and the cultural association of motherhood and fertility with womanhood, combined to have a deep, far-reaching impact on the young women's experiences and perceptions of life after breast cancer. In a study which involved interviews with men and women undergoing infertility treatment, Clarke *et al.* (2006:109) argued that infertility particularly highlights the "centrality of the body to an individual's sense of self", because it brings under scrutiny, often for the first time, the "power of the body – a power to define the reality of who they are, and to give definition of what they can or cannot become" (p.110). In the case of the young women I interviewed, some felt sure that they would not be able to become pregnant again, while many were uncertain about their fertility status. Many of the young women had to face the possibility that they would now be permanently menopausal, and this was experienced by women across the age range as biographically disruptive, profoundly different to what they and others expected of their age and life stage.

Treatment-induced menopause also brought about a heightened awareness of the inner workings of the body, such as the function of oestrogen, and this was not only the case for women reflecting on their ability to become mothers or have more children.

“I didn’t realise what an important role oestrogen plays in your bodily functions as well, so it keeps your skin nice and supple so if you don’t have oestrogen your skin goes to pot... You’re more prone to, like, aching bones. And the hot sweats, good God! Lank hair... Mood as well, I just tend to be on the low side.” – Ruth

Gender norms informed the young women’s everyday lives with treatment-induced menopause. Reflecting on the impact of the menopause on her ability to multitask, one woman in the second advisory panel meeting stated:

“You don’t feel like a woman anymore.” – Layla

Breast cancer and its treatment set constraints and limitations on who the young women could be or become. The women were starkly aware of this in their everyday lives, negotiating the ongoing effects of treatment. The young women’s experiences and perceptions post-initial treatment were shaped by the intersection and accumulation of gendered assumptions, biographical disruption, and the materiality of their body.

Conclusion

In the preceding chapters, the young women’s accounts were analysed in respect of three key dimensions to their experiences and perceptions of living with a history of breast cancer. This chapter has considered examples of the interactive and cumulative effects of the three dimensions. Firstly, I highlighted the significance of being diagnosed with breast cancer during pregnancy. This experience raised issues across all three dimensions of experiences and perceptions analysed. I have also illustrated the interaction between key dimensions through an account of how bodily experiences, and social expectations about young women’s bodies, combined to shape the nature of their sense of biographical disruption and liminality. Finally, illustrated with the example of treatment-induced menopause, I have

demonstrated that breast cancer had a cumulative impact, pervasive, and affecting all aspects of the young women's lives.

Chapter Ten – Conclusion

Introduction

This thesis has explored the distinctive experiences and perceptions of young women living with a history of breast cancer in the UK. Employing a theoretical framework derived from theories of embodiment, biographical disruption, and gender and intersectionality, it has identified and investigated three key dimensions of experience and perception. There has been very little research about the experience of being a young woman living with a history of breast cancer in the UK, and this thesis has extended knowledge in this area.

This chapter considers the extent to which the methodology and research design enabled the research questions to be addressed, and identifies the key findings of the thesis. I first revisit the theoretical context and research questions. I then briefly return to the methodology and research design of the study, and its limitations. Finally, I set out the key findings, and the avenues for further research which this thesis has contributed to identifying.

Theoretical context and research questions

The theoretical framework, developed from the analysis of existing literature, had three dimensions and was informed by theories of embodiment, biographical disruption, and gender and intersectionality. I adopted an approach to embodiment which positions the body as central to the experience of illness, but understands that such experiences are always given meaning and perceived through social and cultural processes, as well as through a woman's own individual experience and knowledge (Lupton 2012). The review of the literature highlighted the significance of the impact of breast cancer on a young woman's life course, and the theory of illness as biographical disruption (Bury 1982) was identified as a potentially useful concept in understanding this. The concept of liminality (Little *et al.*

1998) was also explored as potentially relevant to young women living with a history of breast cancer. In previous research, liminality has aided understanding of finding oneself ‘betwixt and between’ (Hockey and James 2003:24) the statuses of healthy and ill after cancer treatment. It was also identified as being relevant to the uncertainty regarding fertility which may arise from the position of being a young woman living beyond breast cancer treatment. The research also drew on theories of gender and intersectionality. Prior research has identified the significance of gender in the experience of cancer, as the literature review illustrated, as breast cancer has the potential to challenge a woman’s understanding of herself as a woman (Kasper 1994). An approach to gender was adopted which views gender as being socially constructed yet having meaning and consequences for women’s lives and identities (Young 1990, 2005; Kasper 1994; Thomas-MacLean 2005). Theories of intersectionality have challenged the treatment of women as a homogeneous group, highlighting the particular experiences which arise from being, for example, a black woman (Crenshaw 1989; Collins 1998; McCall 2005). The literature review revealed that much research about breast cancer experience has not paid attention to the ways that other forms of social oppression, such as racism and heterosexism, intersect with gender, and intersectionality was therefore drawn on in order to explore this in the accounts of the young women interviewed.

The literature review, therefore, demonstrated the rationale for drawing on these three theoretical areas in order to explore the accounts of young women living with a history of breast cancer in the UK. The research questions which were developed through the literature review were as follows:

Main question:

- What are the experiences and perceptions of young women living with a history of breast cancer in the UK?

Underlying questions:

- What are the embodied experiences of young women living with a history of breast cancer, and how do they perceive these?
- To what extent does biographical disruption characterise the experiences and perceptions of the young women?
- How are the experiences and perceptions of the young women informed by gender? And are these informed by other intersecting oppressions, such as racism and heterosexism?

Methodology and methods

The research was located within the interpretive paradigm, and the methodology was underpinned by the theoretical perspectives of social constructionism (Berger and Luckmann 1967), social constructionist grounded theory (Charmaz 2006, 2014), feminism (Harding 1987; Kasper 1994; Hesse-Biber 2014), and intersectionality (Crenshaw 1989; Phoenix 2011; Yuval-Davies 2006; Christiensen and Jensen 2012). Crucially, the research aimed to explore the experience of being a young woman with a history of breast cancer from the perspectives of the young women themselves. Key ethical principles from feminism also informed the methodology, as the research aimed to make the women central to the research. Intersectionality was integrated into the research method, as I aimed to construct a study which would be inclusive of the voices of minority ethnic and lesbian women. The stakeholder panel enabled me to incorporate young women's insights into the design of the research and interpretation of the findings. Semi-structured interviews, and the stakeholder panel, facilitated an exploration of the young women's own perspectives, and also allowed me to investigate areas identified as significant through the literature review. The young women were able to reflect back on their experience from the point at which they first found a symptom of breast cancer. Social constructionist grounded theory informed the data analysis, and preliminary analysis was conducted concurrently with data collection. Coding techniques suggested by Charmaz (2006) were utilised throughout the analysis.

Limitations of the research

The small size of the sample enabled an in-depth exploration of the participants' experiences, and resulted in a manageable amount of data, but it also restricts the generalisability of the findings. However, despite being a small scale study, I was able to identify and explore key issues. The inclusion of three women who identified as black or minority ethnic (BME), two who identified as lesbian, and two women who identified as disabled before their diagnosis, means that the voices of these women are contributed to the literature. Nevertheless, it would be wrong to imply that such small numbers are representative of all BME, lesbian, or disabled women in the UK, and future research could seek to include women from these groups in larger numbers. The decision to use semi-structured interviews enabled a shared control over the interview, to some extent, and also the flexibility to explore emergent issues. Data from interviews should be seen as a product of a given social interaction, rather than a straightforward, objective account of 'the truth'. However, the aim of the study was to explore the young women's own perspectives on their experience, and, therefore, interviews enabled this.

Having revisited the theoretical context and methodology of the study, I now identify its key findings.

Key findings

1. Young women experienced and perceived embodied risk

The young women's accounts provided evidence that their perceptions of their bodies were changed as a result of breast cancer and its treatment, and they came to experience their bodies as inherently risky. They experienced a loss of trust in their ability to know what was happening in their bodies, and the persistence of bodily reminders, such as aches and pains, contributed to the women feeling that cancer cells had escaped treatment and were hiding within their bodies. The nature of the embodied risk which they experienced was related to

their age at diagnosis. Young women perceived the return to a pre-menopausal hormonal state, and also pregnancy following treatment, as dangerous and risky.

While previous research has noted the fear of recurrence as significant for people living with a history of cancer, this research identified the way this was experienced through the body, and how it was shaped by the women's age at diagnosis.

2. The young women encountered a dissonance between bodily reality and expectations

The accounts of the young women also demonstrated that they experienced and perceived a dissonance between the reality of their bodies, and their own and others' expectations of their bodies. This arose from the multitude of effects of treatment, and from their own and others' perceptions of how young women's bodies should look, feel, and function. This dissonance was demonstrated in multiple dimensions of the young women's accounts, but one key area which was related to the women's life stage at diagnosis was the impact of treatment-induced menopause. Menopausal symptoms, such as hot flushes and changes to body shape, were viewed by the women as contradictory with their understandings of their bodies as young women.

Further, emphasising sensation and physicality revealed important insights. The new and strange sensations resulting from treatment such as numbness, lop-sidedness, feeling heavier and achier, less strong and mobile, and the loss of libido, all contributed to the dissonance women experienced. The young women were suddenly at odds with their bodies, and the effects of treatment were difficult to reconcile with their expectations of their bodies.

3. *The young women experienced profound biographical disruption and a loss of agency over their life course*

The study showed that young women held assumptions about who is normally diagnosed with breast cancer, and the process of deciding to see their GP and being diagnosed, required a reassessment of what was possible within their biography. The young women's sense of biographical discomfit was exacerbated by the experiences in the health system, and some young women had to push to be referred by their GP because of their age. The young women who were diagnosed while pregnant experienced a further dimension of biographical disruption, because of the challenge to expectations of pregnancy and new motherhood, as well as the impact on the foetus of having to induce an early birth.

The circumstances of women aged below 45 are diverse, as evidenced in this study, but breast cancer often occurred at a key stage in their life course, and there were significant implications, such as a potentially dramatically shortened life span, as well as the impact on family planning. This was a disruption to their anticipated biography. The constraints of treatment timescales meant that, after initial treatment, young women with a history of breast cancer experienced a loss of control or agency over their life course.

4. *Young women experienced a liminal state of profound uncertainty after treatment*

The end of initial treatment was accompanied by a sense of unease and uncertainty in relation to recurrence and survival, and fertility and menopausal status. Their perceptions about the future were altered, and their fears about recurrence were magnified by the possibility of so many decades ahead during which breast cancer could recur. The implications for the young women's life course, in terms of whether they would be able to have children, would not become clear for several years after initial treatment. Even the women who were told that their fertility was normal remained unconvinced and uncertain. Not all of the young women wished to have (more) children after treatment, but uncertainty

regarding menopausal status extended to these women, as they were not clearly defined as pre- or post-menopausal. This meant that young women had to live with an unknown fertility, and an unknown menopausal status, for many years after initial treatment.

This finding contributes to a nuanced understanding of the impact on young women's life course after breast cancer, identifying ongoing uncertainty as central, and identifying age-related dimensions of liminality. The young women's horizons had shifted, but the long-term consequences for their life course would not become clear for many years after diagnosis, and uncertainty about survivorship, and their futures, permeated their everyday lives.

5. The young women had largely negative perspectives on the term 'cancer survivor'

All but three of the young women said that they did not identify as survivors, and a number of them offered a strong critique of the concept of survivorship. In large part this was related to the uncertainty which accompanied the end of initial treatment and continued long after. Rather than wanting to celebrate the end of treatment, they found themselves especially emotionally vulnerable at this point, and this was an ongoing experience. This was in contrast to their own and others' expectations that they would feel returned to normal, and able to move on from cancer. The young women found it difficult to communicate this sense of insecurity to others, perceiving it to be negative, and contradictory to the role expected of them as survivors.

This finding troubles the use of the term 'survivor' in everyday and academic usage to refer to young women with a history of breast cancer. It also contributes to the growing body of literature which critiques the concept of survivorship, and highlights that there is much ambivalence and discomfort with the survivor label amongst those to whom it is applied.

6. *Gendered assumptions had a considerable impact on the young women's experiences and perceptions*

The young women's accounts of the physical impact of breast cancer treatment demonstrated that they felt that their bodies were far from how young women's bodies should look, feel, and function. Identification with feminist politics appeared to mitigate this, but many of the young women experienced the physical effects as a threat to their femininity.

Their age at diagnosis meant that the nature of this threat to their femininity included the implications for their fertility. Women diagnosed during pregnancy experienced a threat to their identity as mothers because, for example, the implications of their treatment raised fears and anxieties about their child's health, and meant that they could not breastfeed. This study further found that the ability to take care of young children was also endangered by treatment, as young women were unable to lift their small children after surgery, and required practical help with childcare throughout adjuvant treatment.

The young women felt responsible for the emotional well-being of others as part of their gender role, and they performed emotion work (Hochschild 2003) in order to protect others from their distress during treatment, their fears about recurrence, and the impact of ongoing physical effects. Young women felt restricted in the emotions which they could share, not only as part of their role as 'survivors', but also their role as women. Previous studies with young women have suggested that the women felt responsible for the emotional well-being of others, but it had not been specifically explored in terms of gender. This study identified that young women performed complex emotion work for others, and also found that, while some of the young women had very young children and did not need to perform emotion work for them, a number had dependent children who they wished to protect from the most upsetting aspects of breast cancer.

7. *Other social divisions intersected with gender to inform young women's experiences and perceptions*

The study found that ageism had an impact in young women's accounts. This was evident in their accounts of the attitudes of health professionals, such as those who dismissed their concerns about a breast cancer symptom. The young women also held ageist assumptions, such as the idea that older women would be less distressed at the physical effects of treatment, which meant they perceived their experiences to be more difficult than older women's.

The women also found it difficult to access appropriate experiential support as they felt that mainstream breast cancer support groups did not cater to their specific needs and concerns as young women. A distinct support gap for young black and minority ethnic (BME) women was identified. BME women wanted support from others from a similar cultural or ethnic background, because there were particular physical and social implications of treatment, which only those with similar experiences would be able to understand or help them with, but they were unable to access this. For the young BME lesbian woman in the study, this experiential gap was even more profound, and she talked about how difficult it was to find other black lesbian women with breast cancer. Together with the finding that young women found mainstream breast cancer support groups unhelpful or even harmful, this demonstrates that, for support to be effectively provided to young women with breast cancer, it must take into account the impact of intersecting social divisions, in addition to age. The lesbian women in the study described the heterosexism which they experienced in the health care system, which adds to existing knowledge of the significance of heterosexism in breast cancer treatment (Fish 2010). For example, a conversation between Vanisha and a nurse about issues related to sex after treatment was framed in terms of sexual intercourse. The accounts of the young disabled women in the study revealed that being diagnosed when they were pre-menopausal had implications for their particular impairments, impacting on mobility and pain.

The literature review found that the majority of previous research has treated the population of women living with a history of breast cancer as homogeneous, paying attention to gender, but neglecting how gender intersects with other social divisions. The above findings contribute to the literature in this area, highlighting distinctive experiences and perceptions concerning age and the position of young BME, lesbian, and disabled women.

Areas for future research

This study has contributed to identifying rich possibilities for future research. The experience of embodied risk was a theme in the accounts of most of the young women interviewed, but there were a few exceptions where risk seemed to be less prominent. Further research could explore why this might be, and this could offer insight into how to provide support and information for young women suffering with the fear of recurrence and embodied risk.

This study confirmed that young women from minority groups had distinctive experiences and perceptions of living with a history of breast cancer, and future research could aim to reach more young women from these groups, rather than treating the population of young women with a history of breast cancer as homogeneous, and only including white, heterosexual, able-bodied women. The nature of impairment is diverse, and future research could therefore aim to include women with wide-ranging disabilities. Further research could also consider constructing a sample specifically to explore the relationship between breast cancer and socio-economic circumstances in the lives of young women. I was only able to interview one woman who was single when diagnosed, and future research could aim to include single young women in greater numbers.

Future research might be conducted to further explore the experiences and perceptions of young women diagnosed during pregnancy, considering the profound impact of breast cancer on their embodiment, perceptions of their life course, and the effect on their gender

identity. This is an under-researched area, and the inclusion of three women diagnosed when pregnant in this study represents a valuable contribution to the literature, but further research might explore their experiences in greater numbers. Women who terminated their pregnancies when they were diagnosed could also be included, and their experiences sensitively explored. Further research from an intersectionality perspective could also explore the experiences of BME and sexual minority women diagnosed with breast cancer during pregnancy. The accounts in Chapter Eight highlighted the lack of support for young BME women, and this may have particular implications for young BME women diagnosed during pregnancy. The analysis in Chapter Eight also revealed the heterosexism which shaped Vanisha's and Ruth's experiences in the health system, and heterosexist assumptions about gender identity and motherhood may also shape lesbian and bisexual women's experiences of diagnosis during pregnancy in particular ways.

The identification with feminist politics appeared to mitigate the experience of breast cancer as a threat to gender identity, and this could be an avenue of further exploration. Further research could also explore the nature of the emotion work which young women performed in their everyday lives during, and long after, breast cancer treatment. Some of the young women described ways that their partners were able to provide emotional support and perhaps performed emotion work in order to help the young women. The emotion work which young couples perform together during and after breast cancer could therefore be an area for future research.

Conclusion

While acknowledging certain similarities with older women, this study has identified young women's distinctive experiences and perceptions of living with a history of breast cancer. Its findings contribute to the sparse literature about this phenomenon in the UK. While the young women I interviewed were sometimes positive about their futures, a sense of uncertainty and risk permeated their accounts and their everyday lives. The young women

found that their understandings of themselves as young women were forever changed, as they had to contend with ongoing physical effects, an uncertain future, and the impact on their gender identity, intersecting with other social divisions.

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Appendices

Appendix A: Table of qualitative studies by country of origin

The following table includes all research which is cited in the literature review and has used qualitative methods to explore women's experiences of breast cancer, organised alphabetically according to the country in which it was conducted.

Author	Year	Topic	Country
Anderson <i>et al.</i>	2011	Younger and older women's concerns about menopause after breast cancer	Australia
Connell	2005	The perspectives of young women with breast cancer	Australia
Connell <i>et al.</i>	2006	Reproductive issues raised by young women with breast cancer	Australia
Coyne & Borbasi	2009	Younger women's perspectives on living through breast cancer treatment	Australia
Dunn & Steginga	2000	Young women's experiences of breast cancer	Australia
Kirkman <i>et al.</i>	2014	Women's reflections on fertility and motherhood after breast cancer	Australia
Morris <i>et al.</i>	2011	Survivor identity and post-traumatic growth	Australia
Perz <i>et al.</i>	2014	Experience of changes to fertility after breast cancer	Australia
Thewes <i>et al.</i>	2003	Fertility- and menopause-related information needs of young women with breast cancer	Australia
Archibald <i>et al.</i>	2006	Chemically-induced menopause and sexual functioning after breast cancer	Canada
Brunet <i>et al.</i>	2013	Women's experiences of a changed body after breast cancer	Canada
Burles	2010	Young women's experiences of serious illness	Canada
Gould <i>et al.</i>	2006	Nationwide consultations with young women with breast cancer	Canada
Sinding & Wiernikowski	2008	Older women's cancer narratives	Canada
Stephenson <i>et al.</i>	2013	Women with breast cancer and the term survivor	Canada
Thomas-Maclean	2004	Women's experiences of breast cancer	Canada
Bilhult & Segeston	2003	Mothers with breast cancer	Sweden
Fallbjork <i>et al.</i>	2012	Meanings of mastectomy	Sweden
Klaeson & Bertero	2008	Sexual identity following breast cancer treatment in pre-menopausal women	Sweden
Lindwall & Bergbom	2009	The altered body after breast cancer surgery	Sweden
Piot-Ziegler <i>et al.</i>	2010	Mastectomy and impact on identity	Switzerland

Liamputtong & Suwankhong	2015	Biographical disruption and management in Thai women with breast cancer	Thailand
Bredin	1999	Mastectomy, body image, and therapeutic massage	UK
Banning <i>et al.</i>	2010	Comparing breast cancer experiences of Muslim Pakistani women living in UK and Pakistan	UK
Lee <i>et al.</i>	2011	Experiences with fertility health services	UK
Lindop & Cannon	2001	Self-assessed support needs of women with breast cancer	UK
McCann <i>et al.</i>	2010	Transitional experiences of women with breast cancer in first year following diagnosis	UK
Patel <i>et al.</i>	2014	Black and South Asian women's experiences of breast cancer	UK
Tighe <i>et al.</i>	2011	Impact of breast cancer in the first year following diagnosis	UK
Trusson	2013	Women's experiences of a 'new normal' following breast cancer	UK
Ashing-Giwa <i>et al.</i>	2004	Breast cancer experiences of African American, Asian American, Latina, and Caucasian women	USA
Avis <i>et al.</i>	2004	psycho-social problems among younger women with breast cancer	USA
Bloom <i>et al.</i>	2004	Quality of life of young breast cancer survivors	USA
Boehmer <i>et al.</i>	2007	Sexual minority women and decisions about reconstruction following mastectomy	USA
Bourjolly	1998	Differences in religiousness between African American and white women with breast cancer	USA
Documet <i>et al.</i>	2012	Breast cancer survivors' perceptions of survivorship	USA
Henderson <i>et al.</i>	2003	African American women coping with breast cancer	USA
Iezzoni <i>et al.</i>	2011	Implications of mobility impairment for diagnosis and treatment of breast cancer	USA
Jabson <i>et al.</i>	2011	Perceived discrimination in sexual minority women's experiences of breast cancer	USA
Gluhoski <i>et al.</i>	1997	Unique stressors experienced by unmarried women with breast cancer	USA
Kaiser	2008	The meaning of the survivor identity for women with breast cancer	USA
Kasper	1994	A feminist, qualitative study of women with breast cancer	USA
Langellier & Sullivan	1998	'Breast talk' in breast cancer narratives	USA
Matthews <i>et al.</i>	2002	The experiences of lesbian and heterosexual patients with breast cancer	USA
Rubin <i>et al.</i>	2013	Difference and disparity in breast reconstruction	USA
Rubin & Tanenbaum	2011	Breast reconstruction decisions among sexual minority women	USA
Siegel <i>et al.</i>	1997	Pregnancy decision-making among women previously treated for breast cancer	USA
Siegel <i>et al.</i>	1999	Age-related distress among young women with breast cancer	USA
Wilmoth	2001	An altered sexual self after breast cancer	USA

Appendix B: The Literature Review

In grounded theory, there is a debate about when the literature review should be carried out (Glaser 1992; Hallberg 2010; Dunne 2011), but it has been argued that a review of the literature is necessary in order to sensitise the researcher to the topic and to identify gaps and appropriate and useful research questions (Suddaby 2006; McGhee *et al.* 2007; Hallberg 2010; Dunne 2011). In Chapters 2-4, I locate this thesis within existing literature about the experiences of young women living with a history of breast cancer. In order to do this, I carried out a literature review, which is “the comprehensive study and interpretation of literature that addresses a specific topic” (Aveyard 2014:2).

Example search terms included, in combination:

- Breast cancer
- Experience
- Qualitative
- Young women OR younger women

As the review progressed, the searches became more specific, for example:

- Pregnancy AND breast cancer
- Biographical disruption AND breast cancer
- Uncertainty AND breast cancer
- Liminality AND breast cancer

The literature for this thesis was gathered from the following sources: relevant academic databases accessible from the University of Warwick library (Applied Social Science Index and Abstracts, Social Science Citation Index, Sociological Abstracts ProQuest, and Web of Science); Google Scholar; the online archives of specific journals (e.g. Sociology of Health and Illness, Body and Society, Qualitative Health Research); the University of Warwick library; and Google Books. I supplemented these searches by reading the bibliographies of relevant books, theses, or journal articles. I also read and made use of other types of sources, such as autobiographies and newspaper articles. Although quantitative research was gathered

and read, the focus of this thesis is on the perspectives of the young women themselves, and, therefore, the majority of research reviewed in the thesis is qualitative in nature. In addition, statistical information was gathered from the websites Cancer Research UK and the Office for National Statistics. Research was excluded if it was not written in English.

Appendix C: Information sheet



An exploration of the experiences and perceptions of young women living with a history of breast cancer in the UK

Information Sheet

My name is Sophie Rees and I am a research student at the University of Warwick. Thank you very much for considering taking part in this study. This information sheet explains what the study is about, what is required from you if you volunteer to take part, and how your views will be used.

What is this study about?

The purpose of this research is to explore the experiences and perceptions of women who have had breast cancer under the age of 45. I want to ask about what it is like to be diagnosed and treated for breast cancer at this age, and to talk about your experiences in the years since you finished your initial treatment. I would really like to talk to you if you:

- ☐ Were diagnosed with primary breast cancer before turning 45
- ☐ Have completed initial treatment (i.e. surgery, chemotherapy, radiation treatment) in the last ten years. If you are currently on Tamoxifen or another long-term treatment you may still take part.
- ☐ Live in the UK

Why is this study being carried out?

At the moment we do not know very much about the experiences of younger women who have had breast cancer. I would like to you to hear about your experiences. Health professionals may be better equipped to provide care for younger women with breast cancer if more is known about the issues important to younger women.

What will I have to do?

If you decide to take part in this study, I would like to interview you about your experiences in relation to breast cancer. I have some topics which I would like to raise, but we do not have to stick to these topics. I hope the interview will be more like a long conversation about your experiences, thoughts and feelings about breast cancer, rather than a list of questions which I ask and you answer. I understand that it may be difficult to talk about these experiences and if you become uncomfortable during the interviews it is absolutely fine to take a break, or to stop the interview.

There are no right or wrong answers, I am interested in what you have to say and the information you share with me is completely up to you. I would like to audiotape the interview, but if you have any worries about being recorded then we can conduct the interview without audiotaping.

How much time would I have to spare?

Interviews will last around one hour. It will be possible to have more than one interview if that will suit you better.

Where will my interview be conducted?

The interview can be conducted at a time and place of your convenience, including in your home if that is convenient.

Will my interview be confidential?

Your identity will be kept completely anonymous, and you will be able to withdraw from the study at any point, including after the interview. I hope to use some of your interview in the research report that I will write, but I will make sure that no information is included that could identify you.

Who is conducting this research?

My name is Sophie Rees, I am aged 26 and currently studying for a PhD at the University of Warwick, and this is my research project. My academic background is in sociology and I studied at Cardiff before coming to Warwick.

Can I get any other information about the study?

If you require more information please contact me. My contact details are at the end of this sheet.

If you require this information sheet and consent form in large print or in another format please contact me.

If you wanted to make a complaint at any stage about this study, please contact:

Deputy Registrar's Office

University of Warwick

Coventry

CV4 6UW

j.horsburgh@warwick.ac.uk

+44 (0)24 7652 3704

What should I do if I want to take part?

If you decide you would like to take part in this study, please contact me by the end of _____
in one of the following ways:
Telephone: 07789 867 440
Email: s.l.rees@warwick.ac.uk

Appendix D: Consent Form



An exploration of the experiences and perceptions of young women living with a history of breast cancer in the UK

Consent Form

Thank you again for agreeing to participate in this study. Please read the following, tick the boxes if you agree and sign at the end:

- ☐ I have read and understood the Information Sheet provided for the study and have been given the opportunity to ask questions about the study
- ☐ I agree to be interviewed for this study
- ☐ I agree to my voice being tape recorded during the interview
- ☐ I understand that personal details about my identity will not be revealed to anyone but the interviewer
- ☐ I understand that my interview may be quoted in publications but there will not be anything which could identify me
- ☐ I understand that my participation is voluntary and I can withdraw from the study at any time, including after the interview has been conducted

Name of participant: _____

Participant Signature: _____ Date: _____

Researcher Signature: _____ Date: _____

Appendix E: Demographic information sheet



An exploration of the experiences and perceptions of young women living with a history of breast cancer in the UK

Demographic information sheet

Interview number: _____

Date: _____

Age	
Occupation	
Relationship	
Children	
Ethnic identity	
Disabilities or other previous health issues	

Appendix F: Interview schedule

Questions/Topics
1. Would you like to start from when you first thought something was wrong? What did you notice? What treatment did they propose? Did you have reconstruction? Are there any long-term physical effects from treatment? How did you feel during ____?
2. Can you talk about what life has been like since the end of treatment? Everyday life; working life; taking long-term treatment; relationships/friendships
3. Can you talk about the ways you think it would have been different for you if you were diagnosed when you were older?
4. When you think about your body before treatment and now, can you talk about how you feel about it? How does your body <i>feel</i> to you now? You don't have to talk about this, but if it's okay could you talk about how it's affected your sexuality and intimate experiences?
5. Did having breast cancer change your plans for the future? For example career plans; family planning
6. Can you talk about how or if breast cancer has affected you as a woman? Has it changed how you see yourself as a woman? In what ways?
7. Can you talk about if breast cancer has affected your relationship with your partner?
8. Do you use the term 'breast cancer survivor' about yourself? Why/why not? What do you think of when you think of that term?
9. Did you feel there were any expectations from others about how you dealt with it? And how about how you are dealing with it now?
10. Did having breast cancer affect your finances? Did it affect your working life or career? Were there/have there been any additional costs for you during/after treatment?
11. Can you describe any positive aspects that have come from your experience?
Is there anything else you would like to talk about?

If appropriate:

1. Can you talk about what it was like to be pregnant when you were diagnosed? How was it going through diagnosis/surgery pregnant?
2. Do you think there were any ways that your ethnic identity shaped your experience of breast cancer?
3. Do you think there were any ways that being a lesbian shaped your experience?
4. Do you think there were any ways that being disabled shaped your experience?

Appendix G: Treatment information

This appendix contains three tables providing the treatment information

Table 5 - Initial treatment

Pseudonym	Surgery	Reconstruction after initial surgery	Chemotherapy	Radiotherapy
Ailsa	Mastectomy	Y	N	Y
Beverley	Mastectomy	N – planning	Y	Y
Catherine	Lumpectomy	-	Y	Y
Charlotte	Lumpectomy	-	Y	Y
Dawn	Mastectomy	N	Y	Y
Evelyn	Lumpectomy	-	N	Y
Faith	Mastectomy	N	Y	Y
Gemma	Mastectomy	N	Y	Y
Hayley	Mastectomy	Y	Y	Y
Joanna	Lumpectomy	-	N	Y
Kim	Mastectomy	Y	Y	Y
Lyndsey	Lumpectomy	-	Y	Y
Melanie	Mastectomy	Y	Y	Y
Naomi	Lumpectomy	-	Y	Y
Olivia	Mastectomy	Y	N	N
Philippa	Lumpectomy	-	N	Y
Ruth	Mastectomy	N	Y	Y
Sarah	Mastectomy	N– planning	Y	Y
Tabitha	Mastectomy	Y	Y	Y
Vanisha	Lumpectomy	-	Y	Y

Table 6 - Follow-up preventative treatment (excluding surgery)

Pseudonym	Tamoxifen	Zoladex	Herceptin
Ailsa	Y	U	N
Beverley	Y	Y	N
Catherine	Y	U	Y
Charlotte	Y	U	N
Dawn	N	N	N
Evelyn	Y	U	N
Faith	Y	U	Y
Gemma	Y	U	N
Hayley	Y	Y	Y
Joanna	Y	Y	N
Kim	Y	Y	N
Lyndsey	N	Y– to protect during chemo	Y
Melanie	Y	U	N
Naomi	Y	Y	N
Olivia	Y	U	N
Philippa	Y	Y	N
Ruth	Y	Y	N
Sarah	Y	U	N
Tabitha	Y	Y	N
Vanisha	Y	U	N

Table 7 - Preventative surgery

Pseudonym	Preventative mastectomy	Reconstruction after preventative mastectomy	Oophorectomy or hysterectomy
Ailsa	N	-	N
Beverley	N	-	N
Catherine	N	-	N
Charlotte	Planning bilateral	Planning	Hysterectomy
Dawn	Contralateral	Y	N
Evelyn	N	-	N
Faith	Contralateral	Y	N
Gemma	N	-	N
Hayley	N	-	N
Joanna	N	-	N
Kim	N	-	Oophorectomy
Lyndsey	N	-	N
Melanie	N	-	N
Naomi	N	-	N
Olivia	N	-	N
Philippa	N	-	N
Ruth	N	-	N
Sarah	N	-	N
Tabitha	N	-	N
Vanisha	Bilateral	Y	Oophorectomy